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UNIVERSITY OF ALBERTA

OBTAINING HEALTH CARE FOR CHILDREN WITH MENTAL RETARDATION: MOTHERS' EXPERIENCES

by

SANDRA MARIE CHOMICKI

©

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE

OF

MASTER OF EDUCATION

IN

SPECIAL EDUCATION

EDMONTON, ALBERTA

SPRING, 1992

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ISBN 0-315-73172-9

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TITLE OF THESIS: OBTAINING HEALTH CARE FOR CHILDREN WITH MENTAL RETARDATION: MOTHERS' EXPERIENCES

DEGREE: MASTER OF EDUCATION

YEAR THIS DEGREE GRANTED: 1992

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Truth is so excellent that if it but praises small things they become noble.

Leonardo Da Vinci

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the faculty of Graduate Studies and Research for acceptance, a thesis entitled Obtaining health care for children with mental retardation: Mothers' experiences, submitted by Sandra Marie CHOMICKI in partial fulfillment of the requirements for the degree of Master of Education in Special Education.

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In memory of Alexis

Abstract

This comparative study examined the experiences of eight mothers in obtaining health care for their children with mental retardation. Four of these women had a child with Down syndrome; four had offspring severely affected. A qualitative methodology, using semi-structured, in-depth interviews was used to complement quantitative data obtained in a preliminary study.

Seven themes emerged from the analysis of the interviews with the mothers of individuals with Down syndrome. These included: child characteristics, co-researcher characteristics and behavior, co-researcher feelings about their experiences, helpful physician characteristics, the influence of the health care service delivery system on mothers' experiences, the nature of hospital experiences, and mothers' opinions on societal issues regarding treatment and care.

Mothers in the group having offspring affected by severe mental retardation shared the same themes as the respondents in the Down syndrome group, but there were variations in the sub-themes that emerged from the data analysis. An additional theme concerning experiences in obtaining a diagnosis for their child was expressed. Finally, in response to a structured question, all mothers agreed that individuals who put them in touch with support services were the most helpful to them when obtaining health care for their offspring with mental retardation.

The implications of the study were reviewed and several recommendations were made. These included; increased training for physicians in the health care needs of individuals with mental retardation, a coordinated service delivery system, recognition of the value and worth of individuals with mental retardation by health

care professionals and the provision of health care services to individuals with mental retardation, across the lifespan.

Acknowledgements

I would like to thank my co-researchers in this study and their families. They welcomed me into their homes and generously gave of their time so that this study could be carried out. I would also like to thank the co-researchers for the encouragment extended to me and for the appreciation they displayed for the thesis topic.

Dr. Lorraine Wilgosh has been an exemplary supervisor during the course of my graduate study and the thesis preparation. I am thankful to her for her patient and careful guidance and encouragement; her enthusiasm for my work, and especially for the parental perspective; and her dedication to my growth as a graduate student.

I would like to thank Dr. Dick Sobsey for his interest in my topic of study, for his encouragement, and for the leadership role he provided in the area of mental retardation. I am grateful to Dr. Everett-Turner and Dr. McDonald for their willingness to serve on my thesis committee, for their patience in reading the manuscript and for their helpful suggestions.

To my parents, who ensured that I had educational opportunities that were not available to them, I owe a deep debt of gratitude. To Peter, my husband, and David, our son, I am most grateful for their cooperation, understanding and unfailing support, throughout my graduate work.

Finally, I would like to express my appreciation to all the individuals with challenging conditions, including mental retardation who have taught me about the unique nature of their struggle and who continue to be my inspiration.

TABLE OF CONTENTS

CHAPTER		PAGE
I	INTRODUCTION	1
	A. BACKGROUND TO THE STUDY	2
	B. DEFINITION OF TERMS	7
II	LITERATURE REVIEW	11
III	METHODOLOGY	27
	A. THE RATIONALE UNDERLYING QUALITATIVE RESEARCH	27
	B. DATA ANALYSIS IN QUALITATIVE RESEARCH METHODOLOGY	28
	C. THE CO-RESEARCHERS IN QUALITATIVE ANALYSIS	29
	D. VALIDITY AND RELIABILITY CONSIDERATIONS IN QUALITATIVE INVESTIGATIONS	30
	E. RESEARCH PROCEDURES	32
	Co-researcher selection procedure	32
	Co-researcher description	33
	The pilot study	34
	Interview procedures	36
	Data analysis	39
IV	RESULTS OF THE STUDY	42
	A. MOTHERS OF CHILDREN WITH DOWN SYNDROME	
	Theme 1 - Child characteristics that necessitated health care	43
	Theme 2 - Co-researcher characteristics and behavior when obtaining health care for their childrenwith Down syndrome	46
	Theme 3 - Co-researcher feelings about their experiences in obtaining health care for her child with Down syndrome	52
	Theme 4 - Helpful physician characteristics in obtaining health care for individuals with Down syndrome	54

Theme 5 - How services have been delivered has been an important part of the co-researcher's experiences in obtaining health care 60
Theme 6 - Hospital experiences at the time of diagnosis of disability and later, have been varied 63
Theme 7 - Societal issues regarding treatment and care of individuals with Down syndrome 68
Analysis of the responses to the question, "What has been most helpful when obtaining health care for your child with Down syndrome 73
B. MOTHERS OF CHILDREN WITH SEVERE MENTAL RETARDATION
Theme 1 - Child characteristics that necessitated health care 76
Theme 2 - Co-researcher characteristics and behavior that assisted them in obtaining health care for their child 80
Theme 3 - Co-researcher's feelings regarding experiences in obtaining health care 84
Theme 4 - Helpful physician characteristics in obtaining health care for individuals with severe mental retardation 87
Theme 5 - Co-researcher's experiences when hospitalization was required for the child with severe mental retardation 90
Theme 6 - How services have been delivered has been an important part of the mothers' experiences in obtaining health care for their child with severe mental retardation 93
Theme 7 - Co-researchers' experiences with obtaining a diagnosis for their child's condition 95
Theme 8 - Societal issues regarding treatment and care of individuals with severe mental retardation 98
Analysis of the responses to the question,"What has been most helpful when obtaining health care for you child with

severe mental retardation 100
C. BETWEEN-GROUP ANALYSIS - THEMES HELD IN COMMON BY ALL THE CO-RESEARCHERS
Theme 1 - Child characteristics 102
Theme 2 - Co-researcher characteristics 103
Theme 3 - Co-researchers' feelings regarding their experiences in obtaining health care for their sons or daughters with mental retardation 104
Theme 4 - Physician characteristics that have helped the co-researchers in obtaining health care for their children with mental retardation 105
Theme 5 - The co-researchers' experiences with obtaining a diagnosis for their child's condition 106
Theme 6 - How services have been delivered has impacted upon the co-researchers' experiences in obtaining health care for their children with mental retardation 107
Theme 7 - Societal issues concerning the treatment and care of individuals with mental retardation 107
V DISCUSSION AND CONCLUSIONS
A. A COMPARISON OF THE RESULTS OF THE PRELIMINARY STUDY WITH THE PRESENT STUDY 109
B. THE EFFECT OF FREQUENT EXPOSURE TO HEALTH CARE SERVICES ON PARENTAL PERCEPTIONS OF SERVICE DELIVERY 112
C. GLOBAL CONCERNS REGARDING HEALTH CARE PROVISION AND SOCIETAL RESPONSES TO THE CARE AND TREATMENT OF INDIVIDUALS WITH MENTAL RETARDATION 113
D. LIMITATIONS OF THE STUDY
LIMITATIONS REGARDING THE SAMPLE 117
LIMITATIONS RETARDING THE INTERVIEW PROTOCOL ANALYSIS

E. IMPLICATIONS FOR PARENTS AND HEALTH CARE PROFESSIONALS 119
F. CONCLUSIONS 123
G. REFERENCES 126
APPENDIX A
TABLE A-1
Percent agreement with questionnaire statements for each of the study groups 137
APPENDIX B
TABLE B-1
Thematic abstraction of N's experiences in obtaining health care for her daughter 140
TABLE B-2
Higher order thematic description of N's experiences in obtaining health care for her daughter 151
APPENDIX C
TABLE C-1
Within-group theme cluster analysis - Down syndrome group 153
TABLE C-2
Within-group theme cluster analysis - Severe group 160

LIST OF FIGURES

FIGURE 1

Flow chart of the content analysis process 40

Chapter I

Introduction

This thesis is an exploration of the experiences of eight mothers with children affected by mental retardation, in obtaining health care for these individuals. It is a comparative study, in which the experiences of mothers of children moderately affected are compared with the experiences of mothers having children with severe mental retardation. This study will describe the results of the analysis of semi-structured, in-depth interviews conducted with these mothers in the summer of 1991. The goals of this thesis were two-fold. First, the researcher wanted to gain a complete understanding of the phenomenon of obtaining health care for individuals with mental retardation. Secondly, the researcher wanted to see if there were differences in the phenomenon that could be attributed to the degree of retardation experienced by the individual in the family. A qualitative methodology, utilizing descriptive data, was chosen because it would best help the researcher achieve these goals.

There are a number of reasons why a study of this nature is important at this time. Health care is often a critical factor in the lives of individuals with mental retardation. Many of them have specific health care needs that require frequent appointments and a variety of specialist expertise. Extraordinary health care needs are likely to put additional stress on a family system whose coping mechanisms are already overburdened. Investigations such as this one provide increased understanding of family functioning as well as increased knowledge of the health care system-parent relationship. In a time of rising health care costs and limited sources of funding, the increased knowledge and understanding gained from

service users would be helpful in providing a more effective and cost-efficient service delivery system. Meeting the extra health care needs of children with mental retardation is an important factor in their ability to achieve to their potential. This factor is perhaps the most important reason of all for the study.

Background to the study

In January of 1990, a questionnaire survey comparing health care concerns among two groups of parents, those with children affected by moderate mental retardation and those with children affected by severe mental retardation was undertaken by the researcher. This was done in partial fulfillment of the requirements for Educational Psychology 501, An Introduction to Methods of Educational Research. Specifically, the study tested the null hypothesis of no differences in health care concerns between these two groups of parents. A similar hypothesis for age effects, preschool and school-age, was also tested. Four health care variables were surveyed including parental perceptions of: the parent-professional relationship, professional competency, health care service and delivery as well as hospitalization services. Fifty-two parents responded to the questionnaire; twenty-seven had moderately affected sons/daughters, and twenty-five had severely affected offspring.

The results of this preliminary study rejected the null hypothesis of no differences in number of concerns due to level of retardation. Significantly more concerns were expressed by parents of children severely affected than by parents of children moderately affected. Similar results were found on the hospitalization variable. Results of this study also indicated a high level of concern, regardless of level of retardation, on the professional competency and the service delivery

variables (See Appendix A). No age differences were found on the four health care variables, however, age differences on the hospitalization variable approached significance ($p = .056$), with the school age group indicating the higher level of concern.

The limitations of survey research became apparent to the researcher while pursuing the preliminary study. The researcher realized that "yes-no" and "short answer" responses could not adequately portray the lived experience of parents in obtaining health care for their children affected by mental retardation. Thus, the preliminary study stimulated the researcher's interest in discovering, in detail, the parental experience of obtaining health care for individuals with mental retardation. Specifically, the researcher was interested in discovering if the group differences indicated in the preliminary study results would also be seen in analysis of interview material. The researcher was also interested to discover if there are common themes that comprise the experience of obtaining health care for individuals with mental retardation. It was also of interest to discover whether these themes would match those found in the literature review for a more generic population of individuals with chronic conditions. Pursuing the topic qualitatively, would also provide the researcher with the unique opportunity of seeing the results of both methods of research investigation on one particular topic. Finally, the combination of results from both methods of scientific inquiry would provide the researcher with a comprehensive analysis and more complete understanding of the topic. The preliminary study, then, provided a number of reasons for the researcher's decision to pursue the topic of parental experiences in obtaining health care for their children with mental retardation. The literature review, conducted for

the initial study, provided additional reasons for pursing this topic, a second time, using qualitative methods of research design.

The literature review conducted for the preliminary study had several limitations. In the first place, few researchers had looked specifically at the parental perspective when obtaining health care for children with chronic, disabling conditions. In addition, there were very few investigations into parental concerns when obtaining health care. Those that did exist, provided anecdotal information from interview material that was obtained in a more cursory fashion, without particular attention being paid to using a systematic method of analysing extensive descriptive material.

A second limitation concerned the perspective taken by the investigators. Many of the articles discussed parental concerns from a health care professional perspective, or were concerned with aspects of health care provision to individuals with disabling conditions that affected the parental perspective but did not directly address it. Many of these studies concerned the nature and effectiveness of health care services provided to children with disabling conditions. Physician, nurse, and allied health professional perspectives were found on the topic of service provision to individuals with mental retardation specifically or with mental retardation being one of a number of disabling conditions.

The third limitation found in the literature obtained for the preliminary study concerned the nature of the group being studied. The bulk of the research explored for the preliminary study looked at the provision of health care to individuals affected by conditions that were chronic, or disabling, or both. The majority of the parental perspective studies included diverse populations of children that included

individuals with mental retardation. Thus the specific health care concerns of parents of children affected by mental retardation have rarely been investigated. It was possible that the concerns of these parents might be somewhat different from the concerns of parents of children with chronic conditions such as spina bifida or cystic fibrosis. Thus, while disabling and chronic conditions have usually been treated synonymously in the research literature, it is quite possible that specific concerns would exist for particular populations of children, including those with mental retardation. These limitations led the researcher to believe that the parental experience in obtaining health care for individuals with mental retardation was far richer than was evident from the literature review.

The preliminary study by the researcher had made certain assumptions. In the first place, it was assumed that parents of individuals with mental retardation had "concerns" regarding their child's health care and how that care was obtained. Health care concerns were defined in terms of variables that the author extracted from the literature review, and that had been identified by other researchers as being areas of concern for parents of children with disabling conditions. These concerns centred around the topics of: the parent -professional relationship, hospitalization services, service delivery and professional competency. This second study was undertaken with no assumptions. It was designed to provide an opportunity for parents to explore, in depth, their experiences in obtaining health care for their offspring with mental retardation. The researcher wished to expand on the findings of the preliminary study and better understand the topic as presented by the published literature. Specifically, the researcher had three objectives: (a) to discover the nature of parental experiences in obtaining health care for children with

mental retardation, (b) to explore the richness of the qualitative method of research investigation including data collection and analysis techniques, (c) to compare the results of the preliminary study and the present study, noting similarities and differences. In order to accomplish the final objective, the researcher decided to maintain the two levels of mental retardation, established for comparative purposes, in the preliminary study. Thus interviews were conducted in families where there was an individual affected by moderate mental retardation and others where there was an individual severely affected.

The term, "parents", was used quite loosely in the research literature when describing study participants. However, few studies documented whether the mother, the father or both parents were actually involved in the study. As mothers are still predominantly the primary care providers of children, especially children with disabilities, it is likely that they made up the majority of subjects used in studies of this nature. In addition, it is likely that, in many families containing children with disabilties, it is the mother who seeks and carries out most of the health care for the child. In recognition of this factor, the researcher chose to interview mothers of children affected by moderate mental retardation and mothers of children severely affected. Specifically, this second study proposed to answer the following question: what have been the experiences of mothers of children with moderate mental retardation and mothers of children with severe mental retardation when obtaining health care services for these individuals?

Definition of Terms

between-group analysis - a comparison of the shared structure in the thematic analysis of two groups of co-researchers (i.e., between groups of co-researchers rather than between individual co-researchers).

bracketing - the process of setting aside one's presuppositions or biases about a topic in order to confront the experience as lived by the co-researcher. Bracketing involves continual self-reflection on the part of the researcher (Osborne, 1989).

coding of the data - the process of labelling the parts of the interview protocol that describe specific aspects of the phenomenon being researched (Berg, 1989).

co-researcher - the individual who describes the experience in phenomenological or qualitative research. The researcher and individual whose experience is being described work in close collaboration with each other, usually engaging in a dialogal interview, therefore the term co-researcher is more appropriate than the term "subject".

Down syndrome - a congenital condition characterized by physicial malformations and some degree of mental retardation, due to an extra 21 chromosome (Miller & Keene, 1987). Individuals with Down syndrome as a group generally achieve IQ scores in the moderate range (i.e., approximately 36-59) on individualized intelligence tests (Magill, 1989; Salvia & Ysseldyke, 1985; Westling, 1986).

grounded theory - the discovery of data through comparative analysis of descriptive material. The opposite of generating theory from *a priori* assumptions (Glaser & Strauss, 1967).

health care - attending to the soundness of body, mind and spirit of an individual, especially ; in this study, a mother's attention to the physical well-being of her

child/adolescent with mental retardation usually involving interactions with professionals trained in the care and treatment of human physical health.

interview protocol - the interview as it has been transcribed, verbatim.

life-world - the everyday experiences of an individual. The uninterpreted happenings in a person's life that constitute his experience and his "world" (Valle & King, 1978).

meaning unit - a relevant portion of the interview protocol that pertains to the phenomenon being described and that is coded for thematic inclusion.

mental retardation - a condition experienced by individuals whose intellectual functioning is significantly below the average, resulting in/associated with concurrent deficits in adaptive behavior functioning and manifested during the developmental period (Grossman, 1983).

negative case testing (interrogative hypothesis testing) - a method of ensuring that the thematic cluster or structure is true for all co-researchers. After describing the theme, the researcher searches all protocols for cases where the theme is not applicable. If such data is found the theme is either adjusted to accommodate the data or is discarded if accommodation is not possible (Berg, 1989).

phenomenological research - a research method that seeks to understand the meaning of experience through descriptions of that experience. It requires that the researcher cleanse herself of all presuppositions or biases concerning the experience so that the structure of the experience can be discovered and described (Polkinghorne, 1981). It is concerned with discovering the essence of the experience, not with causal relationships.

phenomenology - a branch of philosophical study, espoused by Husserl, concerned with the study of a phenomenon as is it experienced. It attempts to understand human experience free of all pre-existing ideas about that experience (Valle & King, 1978).

qualitative research - an inclusive term for a number of research strategies designed to analyze descriptive data, as opposed to numerical data, in a systematic way. Research questions are formulated to explore a topic in detail without reference to predetermined hypotheses (Bogdan & Biklen, 1982).

reduction - the process of organizing or grouping the descriptive data into more inclusive categories from which the structural descriptions of the data emerge.

severe mental retardation - mental retardation where the level of intellectual functioning, as measured by IQ based on Stanford-Binet norms, ranges approximately from 20-35. Standardized IQ and adaptive behavior measures were not available for any of the children whose mothers were co-researchers in this study. For the purposes of this study, a three-fold definition of severe mental retardation was described. Severe retardation was defined as: the label used by the informing physician to describe the child's condition, complete dependence upon others for one's personal care needs, and the presence of at least two other impariments in the severe range.

thematic cluster - coded data that has common elements and provides a description of one particular structural element of the phenomenon.

within-group or between-persons analysis - an analysis of the shared structure or themes across several interviews or between several co-researchers (Osborne, 1989).

This chapter has provided the background information and outlined the purpose for this study. Chapter II will provide a review of the related literature.

Chapter II

Literature Review

The principle of normalization and the consequent deinstitutionalization movement of the 1970's have resulted in greater numbers of individuals with mental retardation requiring generic services, including those of health care (Garrard, 1982). Increasingly, individuals with mental retardation have been moving from large institutional settings to smaller, community-based living accommodation (Ong & Alaszewski, 1988). In addition, infants with disabling conditions are likely to remain in the family home or are placed in foster care settings. This shift in orientation from "institution" to "community" , has resulted in a growing need for community based services, including those of health care (Beange & Bauman, 1990; Garrard, 1982; Howells, 1991; Tesini, 1987; Wilson & Haire, 1990).

Parental and family involvement has been essential to the movement to keep individuals with mental disabilities in the community (Rowitz, 1989). Increasingly, families are choosing to care for children with mental disabilities in the family home and are accessing generic services to meet the needs of all their children, regardless of ability. Children with mental disabilities, especially those in the moderate and severe range, are likely to have more health care needs than children not so affected, due to the etiologies of these conditions (Garrard, 1982; Ziring, Kastner, Friedman, Pond, Barnett, Sonnenberg, & Strassburger, 1988). In addition, the health care needs of these individuals are likely to be more complex than those of individuals not so affected (Ziring et al., 1988). Ziring et al. (1988) reported that chronic health problems were 15 times more common among children with severe mental

retardation than among children with average intelligence. In addition, Rubin, (1987) reported that individuals with mental retardation often had seizure or psychiatric disorders that required anticonvulsant or psychotropic medication for managing these conditions. Newacheck (1989) stated that disabled children, including those with mental retardation, were three times more likely to be hospitalized than nondisabled children, had an average of 11 physician contacts a year, used nonphysician professional services six times more often than their nondisabled peers, and overall, used twice as many health care services as children without disabilities. Beange and Bauman (1990), in a study of the prevalence of medical problems among 251 Australian adults with developmental disabilities, found a high level of medical need among these individuals as well as increased health risk factors and numerous incidents of untreated disease.

A number of studies have reported on the specific health care needs of individuals with Down syndrome. Cooley and Graham (1991) stated that these individuals are at risk for a number of conditions that impact upon their health status. For example, congenital heart disease is found in nearly half of the individuals with Down syndrome. A similar proportion of individuals with Down syndrome experience hearing, vision and obeisity problems. Miola (1987) reported that children with Down syndrome experienced increased vulnerability to infections resulting in more frequent hospitalizations than other children. Finally, Goldstein (1988) reported that adolescents with Down syndrome used secondary health services more frequently and had significantly more chronic conditions, than a random sample of age-matched controls. Thus, because many children with mental retardation often have other difficulties such as seizure disorders, respiratory and

circulation difficulties, as well as digestive and elimination problems, they are likely to require health care intervention more frequently than children not so affected. This intervention often begins at birth, includes frequent appointments with a variety of health care specialists, and often results in repeated hospitalizations.

Glendinning (1983) has suggested that the chronicity of disabling conditions often makes such children and their parents "consumers" of service rather than temporary "patients" of service, which is the usual posture in health care (p. 116). As health care consumers, it is possible that children with intellectual impairments and their families experience unique problems when accessing a health care system designed to give immediate and effective service to individuals who are, for the most part, only temporarily dependent and who access the health care system on an infrequent basis. The increased, and often chronic, need for health care on the part of individuals with mental retardation, is likely to result in specific difficulties and concerns on the part of parents regarding the care and treament of these children.

The diagnosis of mental retardation is most frequently made by a physician, often in collaboration with allied health personnel. This is likely due to the role of the physician as a diagnostician of health impairments, and to the link between mental retardation and related health problems. A number of studies have looked at the manner in which parents have been informed of their child's mental disability and at parental reaction to the disclosure. Glenn (1987) examined the experiences of two groups of parents, those whose children were identified in early infancy (i.e., had readily identifiable conditions such as Down syndrome) and those whose children were identified in later childhood. All parents in this study agreed that the

time of being informed of their child's condition was a critical and traumatic period for them. However, while parents who were informed early could get on with the business of parenting the child, the majority of those whose children were identified later spent considerable time attempting to obtain a diagnosis for their child's condition. This time was described as stressful and as being fraught with anxiety and frustration. The stress of obtaining a diagnosis for one's child was also reported in a comparative study of stress among mothers of disabled and nondisabled children. In that study, Burke, Costello, and Handley-Derry (1989) found that mothers of disabled children indicated that the diagnosis of their child's disability was the hospitalization event that caused them the most stress. Stress due to the lengthy process of obtaining a diagnosis was also reported by Wilgosh, Adams, Morgan and Waggoner (1988). In their summary of familial adjustment to a child with a handicap, these researchers reported that a central theme among families of moderately handicapped children concerned the confusion these families experienced regarding the causal nature and extent of the handicap, prior to diagnosis.

A number of studies have reported on the manner in which parents were informed about their child's disability. Pueschel and Murphy (1986) noted that parents remembered with considerable detail the circumstances surrounding the disclosure of Down syndrome. Strauss and Munton (1985), in a study of the concerns of parents with disabled children, described negative experiences with health care providers at the time of diagnosis. The parents in the study described themselves as being upset with remarks by these individuals, that were inaccurate and lacked sensitivity to their feelings. Parents of ventilator dependent children

expressed feelings of hurt and devastation at insenstive descriptions of their children made by physicians in a study by Thomas (1986). Similarly, Glenn (1987) reported that parents were critical of physicians who diagnosed their child's condition but were relatively uninformed about mental retardation as well as support services that were available to parents. They were also critical of the manner and attitude of individuals involved with the parents at the time of diagnosis. On the other hand, Cottrell and Summers (1990) found that parents could cope with a delay in a confirmed diagnosis if physician's informed them as to their child's progress and as to their efforts in arriving at a positive diagnosis.

A number of studies focused on providing a collaborative and supportive disclosure session for parents of children with Down syndrome. Gath (1985), in a prospective study of babies born with Down syndrome, described the time of informing as "the beginning of an alliance between doctor and parents with the aim of giving the handicapped child and the family a good start in their life together" (p. 395). McCann and Allard (1987) described a team approach to informing parents of the presence of Down syndrome and to providing care at the time of diagnosis. Cunningham, Morgan, and McGucken (1984) compared parental responses to being informed of the presence of Down syndrome in their child. They found that parents provided with a model service did not display feelings of dissatisfaction and anger towards the physician, provided that they were told soon after the birth, with both parents present, and were given accurate and complete information. Thus, while some studies found that "informing" physicians had limited knowledge of mental retardation and presented the diagnosis in a manner that was oblivious to parental feelings of anxiety and disappointment, a number of researchers have

found exemplary approaches to informing parents of their child's disabilty in a constructive and mutually enhancing manner.

Newacheck (1989) stated that children with disabilities have almost three times as many contacts with physicians as do their nondisabled peers, during any given year and use nonphysician professional services six times as much as their nondisabled peers. They are also twice as likely to require devices to assist with vision, hearing and mobility . Phillips and Brostoff (1989) reported that a hospitalized disabled child could conceivably receive services from as many as 10 different disciplines located in the facility. Similarly, in a survey of 22 parents of long-stay children, Alcock and Mahoney (1990) found that most of the respondents (77%) had met more than 27 professionals, who were providing care to their child while in hospital. Thus, parents of children with disabilities access many health care professionals to meet their child's needs and require a number of different health care services in order to care adequately for their child.

Informing themselves as to the availability of services as well as locating those that best meet their needs can be a time-consuming and frustrating process. Participants in the Strauss and Munton (1985) study reported that a major problem in obtaining services for their children was the delay they often experienced in obtaining referrals for services. It is often the case that services and treatment facilitites lack the kind of integration, both in location and personnel, that would facilitate access (Glendinning, 1983; Schild, 1982; Stone, 1989; Turnbull, 1983). These reports were echoed by Walker, Epstein, Taylor, Crocker, and Tuttle (1989), who surveyed 910 parents of children with chronic health problems, including mental retardation. The most frequently mentioned aspects of speciality care that

the respondents would change were inefficiency and long waiting periods for appointments and treatment. Seventy-two percent of respondents also indicated that they needed help in obtaining all of the services their child needed. Coping with this high need for service is especially difficult for parents who reside in rural areas, or for those individuals whose children are in wheelchairs or require special equipment for transportation and positioning. It also presents particular problems when both parents work outside the home, or in single parent situations, where many schedules must be organized around appointments made to meet the child's medical needs.

In light of this information, it is not surprising to find references in the research literature to the provision of coordinated care and collaboration on the part of health care professionals. Hutchins (1985), in a retrospective review of the changes in services to individuals with mental retardation, emphasized the importance of this kind of service delivery. A number of researchers cited the emerging role of the family practitioner or pediatrician as the primary care provider and coordinator of services. Howells (1986) stressed the importance of a community-based, primary health team in meeting the needs of individuals with mental retardation who were living in the community. In a later report, he emphasized that it was the general practitioner to whom individuals with mental retardation turned, when they required health care (Howells, 1991). Cole (1987) described the organization of care through the primary care physician as one of several fundamental components of an integrated community-based health care delivery system. An extension of this concept was described by Griswold, Msall, and Cooke (1987), who also emphasized the importance of linking the primary

health care provider with a university affiliated medical facility. Such a facility could provide the depth of expertise and service often required in the managment of chronic conditions including mental retardation. Finally, McCubbin and Huang (1989) noted that one of the biggest challenges facing parents of children with handicaps is the time necessary to locate and coordinate all the services required by these children. They suggested that providing assistance to parents in locating resources and programs is a valuable source of support in helping the parents cope with the child's care. In summary, parents of children with chronic conditions, including mental retardation, frequently required the services of numerous health care specialists. Lack of a coordinated system for delivering these services to parents has resulted in a fragmentation of care. Researchers have suggested that the primary care physician concept should be utilized as a mechanism for coordinating services to this population.

The need for a collaborative relationship between parents and health care professionals has been documented in the literature. Several researchers have described the critical role played by parents in the provision of health care to their child, both at home and while in hospital, and the need for health care professionals to recognize the contribution of the parents. Linley (1984) reported a number of themes that emerged from interviews with four mothers of children with health problems. The most significant theme for these mothers was the importance they placed on being allowed to participate in their child's care. Being excluded from decision-making regarding their child's health care resulted in feelings of helplessness and incompetence. Neilson (1990) stated that "parents should be able to see themselves as the most important members of the professional team to whom

care of their child is entrusted" (p. 19). Phillips & Brostoff (1989) emphasized that parents are the health team coordinators and need to have their perceptions recognized by health care professionals. Dane (1985) noted that parents had more knowledge and expertise about their child than any professional and that their expertise needed to be validated. As well, Thomas (1986) noted that the parents of ventilator dependent children wanted to be listened to and to be shown respect for their ability to assess their child's needs.

Meeting parental and professional goals when the hospitalization of a child is required, presents particular problems. In their study on maternal stress and repeated hospitalization, Burke, Costello, and Handley-Derry (1989) found that, in repeated hospitalizations, mothers of disabled children were concerned that nursing staff would not be able to maintain the procedures and routines they had developed to cope with their child's disabilities. They also perceived staff as not being as skilled as themselves in carrying out the child's daily living activites, including such things as feeding, toileting and mobility. On the other hand, Gill (1987a, 1987b) reported that not all nurses looked favorably upon parental participation in their child's care while in hospital. Those nurses who were comfortable with parental involvement had certain characteristics. These nurses were married, were parents, were supervisors, received their nursing training in college and worked in two particular hospitals included in the research study.

Robinson (1985) stated that hospital personnel largely determined the extent of parental involvement in the child's care while in hospital. By maintaining control of parental participation they put parents in a "double bind" situation. According to this author, "double bind" situations in health care occurred in the following way.

Parents are the primary care providers in the home, where they gain expertise in the management of their child's condition. Providing care in the home is symmetrical or parallel to the provision of care in the hospital. Thus, when their child is hospitalized, parents expect that their role will be a symmetrical one to that of hospital personnel. However, once admitted to hospital, the relationship is no longer symmetrical but is regarded by hospital staff as a giver-receiver relationship that is complementary rather than symmetical. In that relationship the givers are the hospital staff and the receivers are the patient and parent. This situation negates parental expertise and involvement in the child's care that is detrimental to the parent's self-esteem and confidence. If parents refuse to accept the complementary relationship and are critical of hospital routines as they affect their child, they may become assertive, or they may withdraw their involvement. This behavior is viewed by staff as either interfering or lacking interest in the child's progress. Thus both parents and staff are caught in a "no-win" situation, creating the "double bind". To avoid this situation, Robinson (1985) suggested a mutual participation model that recognized the unique roles of parent and professional in the restoration of health. She emphasized the importance of the primary care nurse in establishing care plans, including mutual participation, in consultation with the parents.

Several other researchers reported on related behaviors that supported Robinson's conclusions on the need to recognize parental involvement. Dane (1985) noted that parents were "life-long advocates for their children" (p. 509). McCubbin and Huang (1989) reported that maternal coping behaviors were positively related to the child's health status. In the light of the research presented, it would appear that the acknowledgement, by health care personnel, of parental

involvement in providing for their child's health care needs is a vital component of a cooperative parent/professional relationship.

The topic of professional training in the provision of health care to individuals with mental retardation has been addressed by a number of researchers. The deinstutionalization movement resulted in a change of focus in the care and treatment of individuals with mental retardation. This movement saw individuals move from large, self-contained institutional care settings to smaller, community-based settings located in the community. This resulted in a change in focus towards the needs of these individuals, from a medical based model to one that looked at their needs from a developmental perspective. As a result of deinstitutionalization, many general practitioners and pediatricians now have individuals on their patient list who have disabling conditions, including mental retardation. Their ability to meet the needs of these individuals and their families is likely to be a function of the extent of physician training and experience in mental retardation.

The need for physician training in the specific health care needs of children with mental retardation, and in the availability of community services for these children and their families, was reported by several researchers. Ayer (1984), in interviews with 132 mothers of school children with severe mental handicaps, found that only one percent of these mothers had obtained information about practical in-home assistance from their family doctor. Singh & Winton (1984), in a survey of practicing physicians, found that many had limited knowledge of the specific problems experienced by these individuals and their families, and knew of few community services available to meet the needs of these families . These same researchers found that physician awareness and knowledge increased significantly

after respondents were mailed detailed information about community services and supports available to families of individuals with mental retardation. Starrett (1985) addressed the issue of the importance of primary care physician early identification and referral for assessment, of children with developmental disorders. Similarly, Altman (1984) described health care professionals as being "the gatekeepers of information and services" (p. 322). Thus training in mental retardation and knowledge of community resources are important aspects of health care provision to this population.

Several researchers have discussed the inadequacy of physician training in mental retardation. Willer, Ross, and Intagliata (1980), in a survey of 64 medical schools in the United States, reported that almost half of these schools presented limited coverage of mental retardation and offered minimal clinical experence in that area. Similar information was reported by Lesser (1986), who noted that at the undergraduate level, curriculum tended to be uncoordinated and disjointed and lacked an essential clinical component. This situation appears to be changing somewhat in the light of other evidence. Guaralnick, Richardson, and Heiser (1982) described a curriculum in handicapping conditions that was provided in a pediatric residency program. The curriculum was designed to train future pediatricians in the developmental, assessment, interdisciplinary and ongoing health needs of the child with a disability. An undergraduate training program that offered training in the first, third and fourth years of medical school, was described by Cohen and Diamond (1984). As well, an in-service program for physicians serving children with disabilities was described by Powers and Healy (1982). This program was multidisciplinary in order to increase physicians' knowledge of

handicapping condition as well as community services and resources. Libb and Eklund (1987) attempted to evaluate the success of university affiliated facilities (UAF) to train physicians for positions of leadership in mental retardation within their particualar disciplines. They reported that approximately 25 % of the graduates of these programs filled positions of leadership in the service delivery system. Bradley (1988), in a retrospective study, reported that, although physician training facilites were increasing the time spent on issues of mental retardation, graduates still felt that they needed further training and information. The main areas of concern for these practicing physicians were communication with individuals and families as well as knowledge about community resources. In summary, the research revealed that physicians need training in the specific health care needs of individuals with mental retardation, and the availability of community services and resources. While some undergraduate and graduate training programs exist, the literature would suggest that such training is still inadequate to meet the growing need created by the growth of the community living perspective.

A number of research articles and studies also described physician and allied health care professional attitudes towards individuals with mental retardation. Cormier (1982) stated that professionals working with physically disabled individuals often convey negative or ambiguous attitudes. She attributed this partly to the social pathology perspective toward disability, taken by training institutions. Nursey, Rhode, and Farmer (1990) compared the attitudes towards mental handicap of 132 parents and 197 physicians. They reported that physicians underestimated the positive attitudes of parents towards their child's quality of life and their child's place in society. Physicians expected parents to be less positive

about their offspring than the parents actually were and indeed, than physicians were. Similar results were reported by Wolraich and Siperstein (1983), who compared prognostic impressions of a number of professional groups including physicians. They found that physicians were more pessimistic about the abilities of adults with mental retardation, than were psychologists or educators. Goodman and Cecil (1987) reported on early intervention referral practices of pediatricians. They found that these physicians were reluctant to refer children with mild retardation to early intervention services. These researchers attributed these results to physician training which views all retardation as being organically based and hence immutable. Respondents were reluctant to refer children until they could be assured of their diagnosis. On the other hand, several researchers have reported on the influence of increased contact with individuals with disabilities in the formation of positive attitudes towards these individuals. Ryan (1983) discussed the importance of nurse training and clinical contact with individuals with mental retardation, and the present lack, there of. Similarly, Bickley (1988) expressed the need for dental professionals to have contact with individuals with mental handicaps at the undergraduate and pre-qualification levels. On the other hand, occupational therapists, trained in the habilitation of individuals with disabilities, expressed very favorable attitudes towards these individuals (Benham, 1988).

Several researchers reported on physician characteristics that were important to them in providing for their child's health care needs. Glendinning (1983) reported that parents of children with disabilities varied in their use of general practitioners for their child's health care. However, when they did chose to use a particular practitioner it was because the physician possessed certain characteristics.

These included: a valuing of the parents' knowledge and judgement about the child's condition, a quick response to parental concerns regarding the child's health status, as well as an understanding of the non-medical needs of the child and family. Parents have reported the need for medical personnel to be sensitive to the specific health difficulties their child might be experiencing (e.g., recognition of a malfunctioning cranial shunt in an individual with hydrocephalus) and to display competency in carrying out related procedures (Glendinning, 1983). Nursey et al. (1990) reported that the parents in their study valued the support of well-informed, honest and sympathetic physicians.

In summary, the literature suggested that children with disabities or chronic conditions were likely to require a variety of health services and the expertise of a number of health care professionals. Children with disabilities were also likely to experience repeated hospitalizations that presented particular difficulties, especially that of parental participation in care. Accessing appropriate services and treatment for their child, locating competent health care professionals with whom they could develop a cooperative relationship, and coping with repeated hospitalizations represented areas of concern for many parents of children with disabling conditions. However, many of these reports documented parental needs and concerns from a professional perspective rather than from a parental point of view. In addition, many of the studies reported on research where mental retardation was only one of many disabling conditions that made up the data base. Mental retardation is likely to present specific health care concerns among parents whose children are affected. Degree of retardation is also likely to impact upon parental perspectives of health care difficulties. Individuals labelled as severely intellectually

impaired often require more hospitalizations and different expertise than individuals affected by moderate mental retardation (Black, Cohn, Smull, & Crites, 1985). They are also more likely to be placed in institutions because of their health care needs, than their moderately affected counterparts (Cole & Meyer, 1989; Conroy, 1985). It is possible that degree of retardation would influence the number and nature of the difficulties that parents experience when obtaining health care for these children. This study will explore the experiences in obtaining health care of two groups of mothers, one group with a family member affected by Down syndrome; the other group with a son or daughter affected by severe mental retardation. The next chapter will cover the design of study, and the methodology employed in collecting and analysing the data.

Chapter III

Methodology

The purpose of this chapter is two-fold. First, a brief description and validation of the rationale in which qualitative research is embedded will be given. Then the application of that rationale to the method of data collection and analysis used in this particular research study will be outlined.

The Rationale Underlying Qualitative Research

Bogdan and Biklen (1982) described qualitative research as "an umbrella term to refer to several research strategies that share certain characterics" (p. 2). They went on to describe these characteristics in terms of the kinds of data collected and the focus of the data collection. Qualitative research, they stated is not structured around a number of specific questions designed to validate hypothetical constructs. Rather, the methodology seeks to explore a particular question in its entirety, by going to the source of the data, the individual or setting itself. Using an inductive process approach, qualitative researchers reach conclusions drawn from a careful and systematic analysis of descriptive data. This systematic analysis involves a gradual process of reduction until the essence or meaning of the experience is extracted from the descriptions of the experience itself.

This research method has its roots in phenomenology, an approach to understanding and interpreting human behavior, attributed to Husserl, a German philosopher of existential thought. The phenomenoligical approach requires a return to the phenomenon itself, as individuals experience it (Colaizzi, 1978). One of the most common methods of capturing the experience of a particular phenomenon is to engage in a dialogal interview with the individual or co-

researcher who describes or illuminates the phenomenon as experienced. This experience, or specific life-world of the interviewee, is the raw data that is provided for analysis (Valle & King, 1978). The individual's experience is pre-reflective, that is, it has not yet been reflected upon by the co-researcher. In describing the experience the individual moves from a pre-reflective to a reflective state (Valle & King, 1978). It is in the description of the experience that meaning becomes evident. However, for the researcher to accurately ascribe meaning to the experiential raw data, she must put aside all presuppositions or prejudgements about the topic. She strives to achieve a state of presuppositionlessness (Polkinghorne, 1981a). This is accomplished by a process of bracketing whereby the researcher first searches for her/his personal assumptions about the data, lays out these assumptions and then attempts to look at the data in a fresh manner, absent of personal bias or preconceptions. It is by consciously bracketing and rebracketing throughout the process of data analysis that the researcher is able to contact the phenomenon itself and to extract the true meaning from the data as intended by the co-researcher (Valle & King, 1978). This extraction of meaning is performed inductively using a unique form of data analysis, content analysis.

Data Analysis in Qualitative Research Methodology

Berg (1989) applied the term "content analysis" to the process of coding descriptive data into categories. According to Berg, interview data can be coded on two levels; manifest content or surface structure of the data (i.e., what is said) and latent content or deep structure (i.e., the symbolic meaning of what is said) or a combination of both levels. It is the coding of data, that is, assigning categories to the data, to each meaning unit extracted from the data, that grounds these categories

to the data from which they are taken. It is in the repetition of these categories over repeated interviews that the coded categories become theory, grounded in the data. Unlike quantitative or statistical analysis which proposes to prove or disprove a logically deduced hypothesis or theory, qualitative analysis makes no a priori assumptions about the data but instead codes the interview data according to the interviewee's intent. The theory emerges through unbiased analysis of the data, as it was intentioned by the interviewee. It is this grounded theory that is the objective of qualitative analysis (Glaser & Strauss, 1967).

The Co-researchers in Qualitative Analysis

When engaging in qualitative research, the term co-researcher is preferred to subject as it better reflects the reciprocal and cooperative relationship between interviewer (i.e., researcher) and interviewee (i.e., co-researcher) as they engage in the dialogal interview (Osborne, 1989). According to Becker (1986), co-researchers should be directly involved in the question or experience being researched and they should have a variety of experiences regarding the topic. In addition they need to be willing to share these experiences. Becker also stated that the researcher must decide whether co-researchers with diverse experiences or those who represent a more homogeneous experiential repetoire would be best suited to the topic of investigation. In addition, she states that the number of co-researchers chosen also varies considerably among researchers from less than five co-researchers to over fifty. Wertz (1984) suggested that the number of co-researchers be chosen on the basis of their ability to illuminate the topic, to describe the phenomenon being researched. According to Wertz the researcher uses enough

people until she/he is comfortable with the idea that the same structure is coming up (i.e., that the themes are repeating themselves).

The choice of co-researchers is one factor that impacts upon the integrity of the research study. Just as the accuracy with which the sample reflects the population being studied is an important factor in determining both the reliability and validity of a statistical analysis, so too in qualitative analysis, the co-researcher's descriptive accuracy and completeness are important components of the investigation. The perspective taken by qualitative methodology on reliability and validity considerations will be discussed next.

Validity and Reliability Considerations in Qualitative Investigations

When carrying out qualitative research, validity and reliability issues take on a somewhat different perspective from that taken in quantitative studies. For the most part they are not treated as separate entities but co-exist within the investigative process. That is, reliability issues concerned with the replication of results and validity issues that centre around causal-relational and generalizability factors, become one issue of the extent to which the results of the data analysis truly reflect the experience as experienced by the co-researcher(s). These issues then are reflective of co-researcher selection and data analysis technique and expertise. Specifically, these issues are connected to the type(s) of question(s) asked, the researcher's interview skills, the ability and willingness of the interviewee or co-researcher to illuminate the topic, and the integrity of the data interpretation. In other words, validity and reliability issues centre around the completeness and accuracy of the interview questions and responses, as well as the researcher's consistency in interpreting the data across interviews.

Choosing co-researchers who are both willing and able to completely articulate their experience with the phenomenon being researched is essential. It is also important to choose a convenient time and comfortable space where both co-researcher and interviewer can be at ease. Providing adequate time so the co-researcher can be complete in her/his description is also essential. Finally, an empathetic and relaxed relationship between the two individuals engaged in the dialogue is critical to capturing the experience in a reliable and valid manner (Becker, 1986).

The ability of the researcher to code themes consistently and to adequately bracket his/her own biases and preconceptions regarding the topic are central to the issues of reliability and validity of the research. The concept of bracketing, rebracketing and presuppositionlessness have already been discussed. In order to faciliate this process, several checks on theme coding during content analysis have been suggested by Berg. He has suggested employing "interrogative hypothesis testing" (Berg, 1989, p. 123) in which the analyst suggests a theme or hypothesis and searches for cases in the protocols that do not fit the theme. If such cases are found they are either discarded or the hypothesis is restructured to include the case. A final examination of all the cases within the protocol to determine fit is then made. In order to prevent possible compromises of the data using this method, he further suggests: (a) that at least three examples be provided to validate any assertion made from the data; (b) that examples illustrating the case be included in the analysis; (c) that analyses should be examined by an individual, independent of the study to ensure that the themes drawn are indeed well documented and finally, (d) that

inconsistencies be discussed and examined in order to ensure the integrity of the overall pattern of analysis.

Research Procedures

Co-researcher selection procedure.

The purpose of this study was to explore the experiences of mothers in obtaining health care for two groups of individuals, those affected, since birth, by moderate mental retardation and those severely affected. The preliminary study had targeted these two groups of individuals. It was possible that a subset of preliminary study participants would be interested in engaging in the qualitative research study. An invitation to these individuals was attached to the preliminary study questionnaire. Those interested in participating in an in-depth interview with the researcher were requested to either complete the information form and mail it to the researcher, or indicate their interest by telephone. A total of 13 mothers indicated that they were willing to participate in the interview process. Several months elapsed between consent and follow-up and 2 mothers subsequently indicated that they preferred not to be interviewed due to busy schedules. Eleven individuals were then left from which a sample could be taken. Upon contact, two mothers indicated that their child had acquired mental retardation in late infancy. As the mental retardation experienced by these children was not congenital, they could not be included in the study. One mother of the remaining nine individuals was chosen to be interviewed for the pilot study. This left eight individuals, four of whom had children with Down syndrome and four of whom indicated that their sons or daughters were affected by severe mental retardation. Because individuals with Down syndrome typically manifest a level of retardation in the moderate range,

the researcher decided to incorporate these individuals into the study rather than search for a more varied sample that exhibited moderate mental retardation.

As all respondents had volunteered to be interviewed, it was assumed that they were willing participants, that they had considerable experience in obtaining health care for their offspring with mental retardation and could articulate these experiences. These individuals will be called interviewees or co-researchers in keeping with the qualitative perspective.

Co-researcher description.

The mothers of individuals with Down syndrome ranged in age from 34 years to 57 years, with a mean age of 41.75 (SD = 9.2). The children with Down syndrome ranged in age from four years to fourteen . The mean age for the group was 9.5 years (SD = 3.5). One child was of preschool age, two children of upper elementary school age and one was a teenager. One individual with Down syndrome was a female while the other three were male. There were siblings present in all families except one. All co-researchers were birth mothers except one who was a foster mother. However, as she had parented the child from the age of four months, her participation in the study was judged to be acceptable, in spite of this difference. All mothers in this group possessed university degrees except one who had a high school diploma and some post secondary education. Two mothers were employed outside of the home, all were married and lived with their husbands in the family home, which they owned. They lived in various neighbourhoods in a western Canadian city.

The four mothers of children with severe mental retardation ranged in age from 31 to 46 years with a mean age of 35.25 (SD = 6.2) for the group, making

this group somewhat younger than the mothers of children with Down syndrome. The children in this group ranged in age from three years to thirteen with a mean age of 6.5 years, (SD = 3.5), also somewhat younger than their counterparts with Down syndrome. Two of these children were preschoolers, one was in primary school and one was a teenager. Once again, only one of the individuals with severe mental retardation was female, a finding in keeping with higher prevalence figures for males. There were siblings in all families One mother possessed several university degrees, two mothers had high school diplomas and one mother was a college student. One mother was employed outside the home. Three mothers were married and lived with their husbands, while one mother was divorced. Three mothers co-owned their homes while one mother lived in a rented apartment. These co-researchers also lived in various neighbourhoods in a western Canadian city.

Careful attention has been paid to maintaining the confidentiality of the interview protocols and the anonymity of the co-researcher. To do this the researcher has identified the participants by a randomly chosen letter of the alphabet.

The pilot study

A pilot study was undertaken for three reasons. First, the researcher wished to test the interview questions and interview format, and to finalize standardized procedures for the interviews and analysis that would be used for the thesis data. Second, the pilot study provided data for a theme analysis which was used to determine the reliability of the analysis process. Finally, the interview data was used to provide training for the author in the use of the computer program

Hyper Qual, which the author intended to use for the analysis of the thesis interview data.

K., a foster mother of two, had volunteered to be interviewed and was chosen as the pilot study co-researcher because she was parenting two adolescents with mental retardation. One of her foster sons had Down syndrome. The other son had a seizure disorder as well as a behavioral repetoire characteristic of autism and severe behavior disorder. Both individuals had been with the family for nine years. Interviews with K. took place in April, 1991. There were four interview sessions in which data was collected, two of which were corroborative interviews. The first interview was submitted to an interrater reliability check once it had been coded. This was accomplished with the assistance of a doctoral candidate who had considerable experience in qualitative research and analysis. A transcript of the interview was given to this individual who coded the complete interview, blind to the author's themes but cognizant of the research question. This coded transcript was given to the author who chose every fifth page of the interview to compare coded themes. Using the formula for calculating the reliability of time sampling (Alberto & Troutman, 1986), adapted to the present context, agreements divided by agreements plus disagreements, multiplied by one hundred, a reliability coefficient of 90% was calculated . This was deemed adequate by the author and her advisor. In addition, the author kept a personal journal of events during the pilot study and was conscious of bracketing personal biases. Following the coding of the pilot study interview as well as the first thesis interview, the author met with the principal advisor to discuss the possible influence of personal biases on interview

coding. The two corroborative interviews served as a final check on reliability/validity of the data coding.

The computer program Hyper Qual was used to analyze the pilot study interview data. However, the researcher decided not to use that program for the thesis data because; it was time consuming to use, generated a large amount of paper, and could only be used in the initial coding of data. In addition, after completing the pilot study, the researcher found that tables could be as effectively employed as the computer program for the data analysis. Once the pilot study results were finalized and submitted to the thesis advisor for review, the data collection for the thesis was begun.

Interview procedures.

All eight co-researchers were contacted and appointments made for the first interview in May, 1991. Initial interviews took place throughout June, July and August with follow-up interviews taking place in September. Emphasis was placed on choosing a date when the mother was relaxed and when the family was not experiencing any stress that might unduly influence each co-researcher's recall of her experiences. Several appointments were resheduled in order to reduce this circumstance as much as possible . Participants had also been informed that the interview would explore the experience in depth and that no attempt would be made to rush the interview. They were assured of anonymity and of their freedom to withdraw from the project at any time. The author was careful to provide sufficient time both for the data collection and corroborative interviews so that each interviewee could be exhaustive in her elaboration.

Becker (1986) suggested a three-stage interview process when conducting qualitative analysis. These included the structuring or "get acquainted" interview, the data collection interview and the collaboration, or verification interview. Only two interview stages were deemed necessary for this particular thesis. As the author had several telephone contacts with all the co-researchers during which time the purpose of the study was outlined and rapport was established, the first interview involved a combination of the structuring and data gathering stages. This interview lasted from two to three hours and took place at the home of each co-researcher, at the kitchen or dining room table on which the tape recorder was placed. Each collaborative interview took place in September, 1991 at which time the co-researcher was given a copy of the transcribed interview. Becker (1986) stated that "the purposes of the corroborative interview are to check the interviewer's understandings of the data and to test the limits of the previously elaborated descriptions " (p. 117). This interview served as a check on the accuracy of the information and provided an opportunity for each co-researcher to examine the meaning units as highlighted by the researcher and the themes assigned to these meaning units. In all cases except one, the transcript was read orally to the co-researcher with pauses at each meaning unit when the co-researcher was invited to comment or elaborate. One mother chose to read the transcript to herself and elaborated when necessary. The corroborative interview was again recorded, transcribed and analyzed, thus providing a more complete elaboration of each co-researcher's experience. Except for three instances, the corroborative interview was completed in a two to three hour session. In two instances a second corroborative interview was required and for one particularly long interview, a third

session was held. It should be noted that the co-researchers supported the researcher's analysis and sought only to clarify or elaborate on statements made at the data collection interview.

The data collection interview was largely semistructured, as only two specific questions were asked of the co-researchers allowing the interview to develop freely. The co-researchers were asked to "tell me (the reseacher) about your experiences when obtaining health care for _____ (the name of the child with the disability)". The term "health care" was defined as those life experiences when the co-researchers' attention was focused on the child's physical health and involved interactions with professionals trained in the care and treatment of human physical health. This included experiences at the birth of the child, at the time of diagnosis, when the child was ill, when the child was hospitalized, as well as any other times when the co-researcher was so focused. In addition, the mothers were also asked the following question: when seeking to have _____ (child's name) health needs met, what have you found to be most helpful?

Throughout the interview process, the author kept a journal to record personal reflections as well as positive and negative responses to the interviews that served to alert her to personal biases. These reflections were shared with the thesis supervisor at several points during the interview and content analysis process.

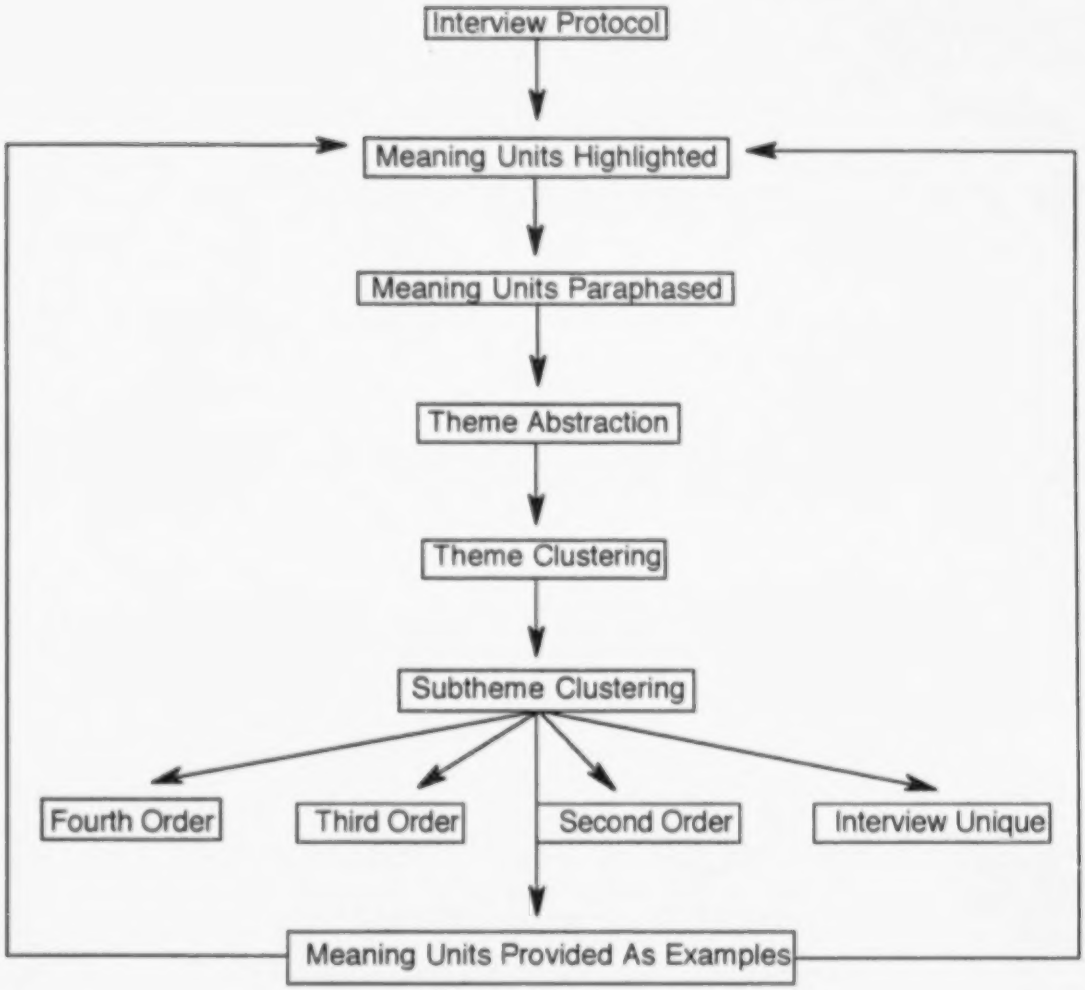
Data analysis.

As was previously stated, qualitative analysis involves extracting meaning units or themes from verbatim text, which are in turn clustered into groups of themes (i.e., thematic clusters) in a process called content analysis. This process is reductionist in nature, reducing the interview protocols to the highest level of

abstraction possible in order to capture the essence of the experience (see Figure 1). In this study, content analysis techniques as described by Giorgi (1975) and Berg (1989) were employed. Each interview transcription or protocol was read and all essential elements (Polkinghorne, 1981) or meaning units were highlighted and labelled, according to the health care themes that were stated (manifest content) or implied (latent content) in the text. Once each interview had been analysed, it was presented in tabular form on two levels of abstraction that served to portray the manifest and latent content of the protocol. In order to accurately determine the manifest content of the co-researcher's experience, the first level of abstraction involved a paraphrase of what had been said. This exercise served to focus the researcher on the exact nature of each co-researcher's intent and to accurately express that intent. This paraphrase was then abstracted to a higher level embodying, whenever possible, the latent content, the deeper message, or symbolic theme that was embedded in the meaning unit (See Appendix B, Table B-1). These themes were then grouped into clusters that formed a common, global theme protraying one aspect of the mother's experience in obtaining health care for her child. To facilitate further analysis, the thematic clusters for each co-researcher were once again presented in tabular form with generalized descriptions of the theme clusters (See Appendix B, Table B-2). Then a between- persons or within-group analysis was conducted in which the four protocols in each group were searched for common themes.

FIGURE 1

Flow chart of the content analysis process



Osborne (1989) has described a comparison of the thematic clusters emerging from interviews derived from several co-researchers as a between-persons or within-group analysis. This analysis was conducted in the following manner. Within the thematic clusters, for each group, specific subthemes also emerged. These subthemes were labelled according to the number of times they were repeated across interviews. When they were consistently repeated by all four co-researchers they were entitled fourth-order subthemes. Repetition by three co-researchers resulted in the label third-order subthemes and so on (See Appendix C, Table C-1 and C-2). Once the between-person (i.e. within-group) analysis was completed using this methdology, the between-group analysis was conducted in a similar fashion, comparing the responses of mothers in the Down syndrome group with responses of the mothers in the severe group. Again the numerical ordering of subthemes emerged, resulting in a final comparison and reduction of the data.

Throughout this analysis, the author engaged in negative case testing (Berg,1989). Using this technique, the author questioned each theme and subtheme to locate instances where the stated theme was not demonstrated by a co-researcher. The author then readjusted the theme or subtheme so that all cases could be included or, if necessary, rejected the theme altogether. The application of a hierarchy of subthemes also enabled the author to incorporate relevant interview data with integrity. In the next chapter, the thematic clusters that emerged from the interviews of each group of co-researchers will be discussed first. Following that, the results of the between-group analysis will be described. In keeping with Berg's (1989) suggestions for verification, examples have been pulled from the protocols to illustrate each thematic cluster.

Chapter IV

Results of the study

In this chapter, the common themes and subthemes drawn from the interviews with mothers of children with Down syndrome, and those extracted from the interviews with mothers of children who are affected by retardation in the severe range, will be described. Each theme will be briefly outlined. This will be followed by a detailed description of the subthemes, amplified by specific quotations from the protocols that present typical illustrations of the subtheme. Following that description, the themes and subthemes common to all of the interviews (i.e., between-group analysis) will be outlined and illustrated in a similar manner. Careful attention has been paid to maintaining anonymity. Alphabetical lettering used to identify individuals or health care facilities has been randomly chosen to further assist this consideration.

Data analysis using the procedure described in Chapter III, revealed seven thematic clusters in the Down syndrome group, and eight thematic clusters in the group of mothers of children with severe mental retardation. Fourth-order subthemes (i.e., those themes repeated by all the mothers in the group) emerged in four of the themes of mothers of children with Down syndrome and in five of the themes extracted from interviews of mothers in the severe group. Seven thematic clusers emerged when the between-group comparison was made. In four of these themes, fourth-order subthemes also emerged. Co-researcher responses to the question, "What has been most helpful in obtaining health care for your child with mental retardation?" were also analyzed using the thematic clustering technique. The results of this analysis are included at the end of the theme descriptions for each

group. In this chapter, the within-group results for each group will be described followed by the between-group results. The results of the content analysis of the interviews with the mothers of childrens with Down syndrome will be presented first.

Mothers of Children with Down Syndrome

Theme 1 - Child characteristics that necessitated health care.

Although each mother's experiences in obtaining health care for her child were unique, the reasons for seeking health care were similar and often related to the specific anomalies associated with Down syndrome. As a result, two fourth-order subthemes emerged in this thematic cluster. In the first instance, all mothers indicated that the child with Down syndrome had required treatment, including surgery, for some form of cardiac deficiency in the neonatal or early infancy period. The mothers indicated that treatment for their children's particular condition was available locally, but that the presence of the heart condition brought additional stress after having been told that the infant was affected by mental retardation. Treatment for the heart anomaly required frequent interactions with a variety of specialist and subspecialist physicians and repeated hospitalizations during the infancy period.

A second fourth-order subtheme was that the child with Down syndrome had related health problems in addition to the congenital heart defect. Several children had digestive tract atresias that were corrected in infancy Two children had vision problems and one of these was a profound impairment (i.e., the child was legally blind). Two mothers spoke of repeated colds and upper respiratory infections. Several mothers spoke of the need for physiotherapy in infancy and the

ongoing need for speech therapy. This tendency to have related health problems resulted in the mother's need to access a number of specialists in order to obtain treatment for each specific condition. One mother said, "I have so many more specialists involved with F. He has an opthamologist and a pediatrician and a cardiologist and an ENT (i.e., an ear, nose and throat specialist) and a dentist and an oral surgeon and it just goes on and on." In spite of these health difficulties, the mothers of three individuals stated that, in their opinion, their son or daughter was healthy now as compared to the infancy period. As one mother stated:

> There are other things that are coming up now. He's got hay fever now and some allergies and that kind of thing. There's nothing extremely serious that we are tied up with. That's another half of the question. N. essentially is doing very well.

Second-order subthemes included statements that reflected the unique characteristics of individuals affected by Down syndrome and were in opposition to stereotypic notions often associated with individuals affected by mental retardation. One mother stated that such children, "Don't read like a textbook necessarily anymore than T. (another sibling) would read like a textbook." Another mother emphasized that her son was not just a sum of the differences that being born with Down syndrome has made but that he had much in common with other children his age. She stated:

> He's a whole person. Down syndrome is just one of the factors in his life. He's a student. He's a learner. He's taking swimming lessons. He plays outside. He has relationships, friendships. He goes to birthday parties.

> He has a brother and a sister. He's learning to play Nintendo. Down syndrome is just one of the factors in his life.

One mother, whose daughter is a teenager, expressed concerns over her daughter's growing sexual maturity. Providing an effective method of birth control and preventing sexual abuse were important themes for this mother. Because a supreme court decision no longer allows sterilization of individuals with mental retardation without their consent, this mother felt that she was being hampered in her efforts to protect her daughter. She expressed her concern in the following manner:

> They (individuals with mental retardation such as her daughter) don't understand what is going on, why. So it doesn't seem right to me that they might have to live with that (an unplanned pregnancy) for the rest of their life when a tubal ligation could prevent that. I really feel that that alternative has to be there and I don't think that the individuals can make that choice themselves. They're not capable of understanding to make that choice. And I think that between a good doctor and parents, that choice should be left up to them in these cases.

In summary, the children with Down syndrome whose mothers were co-researchers in the study all experienced heart surgery and repeated hospitalizations in early infancy. They continued to experience related health problems some of which were directly related to the syndrome. In spite of this, their mothers felt that their children were basically healthy now. Two mothers emphasized the unique behavioral characteristics of their children with Down syndrome and rejected stereotypic notions of the characteristics of these individuals.

Theme 2 - Co-researcher characteristics and behavior when obtaining health care for their children with Down syndrome.

The interview protocols revealed that there were a number of qualities that characterized these mothers and that certain behaviors regarding methods of obtaining health care services for these children were held in common by these women. One fourth-order subtheme emerged from the analysis. All mothers stated that they had acquired advocacy skills in order to obtain services for their children with mental retardation. Three of the mothers had virtually no experience with Down syndrome prior to the birth of their child while one co-researcher worked with individuals affected by mental retardation during a summer vacation. All the mothers stated that their experience with the health care system was also limited prior to the birth of the child with Down syndrome. The birth of the child and subsequent interactions with numerous physicians and other health care professionals as well as repeated hospitalizations had made these women aware of the necessity for initiating and monitoring much of the medical treatment required by their child. Several factors contributed to this particular maternal behavior. One factor concerned the limited communication skills of the child. As one mother stated,"I mean if he doesn't request things and he doesn't, he could end up stuck in a crib all day because he wouldn't complain." She went on to say, " Another kid's going to stand up and cry or complain or ask." Because the individual with Down syndrome had reduced abilities in this area, the mother compensated by performing these functions for her child.

A second factor contributing to the development of advocacy skills on the part of the mother concerned experiences that reduced the mother's trust in the

ability of the health care system to meet her child's needs adequately. For example, conflicting opinions regarding treatment on the part of health care professionals served to validate one mother's concerns regarding her son's walking and to question medical opinion. She stated:

> The "physio" was very concerned about his walking. She had even written a letter, a referral to the physician, about the rotation in the hips and how stiffjointed his knees were and ankles and so on. I mean this doctor thought there was nothing wrong with O's mobility at all. He just didn't really seem to care or be interested. I don't think he did a good job.

Such experiences led mothers to adopt an assertive stance when obtaining health care services for their children with Down syndrome. For these co-researchers, this characteristic took time to develop and arose partly out of an increased knowledge and awareness of the specific deficits associated with Down syndrome. Several of the co-researchers indicated an in-depth knowledge of the etiology of particular health problems and how the presence of Down syndrome impacted upon that condition. As one mother stated, "Everytime I go for an appointment, I make sure I do my homework. I know what I'm talking about on whatever part of F. we're discussing. I read what I can. I know the proper terms and I ask questions." Thus, acquiring advocacy skills required considerable effort on the part of the mother in terms of informing herself about Down syndrome and its impact upon her offspring's health. In addition, the assertiveness associated with advocacy required courage and determination. However, once acquired, it was a skill that could be applied to a number of different areas of service provision

including that of health care. One mother described her experience with learning to advocate in the following manner:

> It takes time to figure out how the system works and during that time you must draw on all your strength and understanding. It's a lot of work is what it is because you're not just working the government system, you're working the medical system. And you know for which doctors you have to get a referral from and which you don't and I mean I just go in and tell them what I want now.

Another mother used these assertiveness skills when a conflict arose between how she wished treatment to be handled and what the hospital wished. Knowing the difficulties associated with hospital admissions and the added stress that situation put on the family, she insisted on a particular course of action. Her experience led her to advocate for a particular treatment situation that put the needs of the child and the family before those of the service provider. She said:

> They (hospital personnel) wanted him to be an in-patient and he's (the child) had it done (dental work) as a day patient. And I just refused to let him go as an in-patient.....So I threatened to phone O. C. (the government official responsible for health care) and tell (that individual) that you are wasting money keeping kids in two days when they only need to be in one. I got a phone call half an hour later saying he could come as a day patient.

Assertiveness training and knowledge building were assisted by interactions with other mothers in similar circumstances. All the co-researchers indicated that they either belonged to a parent support group or networked with other mothers to gain information about specific aspects of the syndrome, what services were

available, and how one could access those services. One mother spoke of a "shared underground network of parents phoning parents saying who do you know that's good in this and who do you know who will do that." One mother described an individual who was particularly adept at locating specific services. She stated:

> I'd say, "N's feet are so difficult to fit, I don't know where in heck I'm going to get a pair of shoes. She knows what are the special outlets in the city and where to go. Or we've been having problems with whatever. Now there are two doctors in the city who really know how to deal with that and she would wind up being the information or referral service.

Advocating for health care that the mother perceived as essential for her child often meant that mothers needed to "shop around" to find physicians with whom they could relate and who had a good rapport with the child. Three mothers indicated that they changed doctors until they found one with whom they were comfortable. One mother indicated that she had changed opthalmologists three times before she found a physician who, she felt, was genuinely concerned with whether or not her child could see. In spite of this, she admitted that seeking second opinions did not always solve the problem of getting the best treatment. She said," So that's the problem with second opinions. If they don't match then who do you believe? You could do this endlessly." This comment was echoed by another co-researcher who indicated that she found the prospect of changing physicians too exhausting to contemplate and had remained with the same physician in spite of some differences of opinion regarding treatment. She stated:

> If that doctor says no then you have to find a referral to another doctor and the whole process of going through all that, of doctor hunting and fiddling

around, gets to be too much after awhile so you simply give up... You only have so much emotional and physical energy to deal with it.

Two mothers stressed their role as primary care provider, including health care, in the family. These mothers indicated that they were the individuals who took the child to medical appointments, administered drugs and other treatments in the home, arranged for follow-up visits and generally oversaw the management of health care needs for all members of the family but especially for the child with Down syndrome. For this reason these mothers felt it was important that they be perceived as part of the care-giving team and that they be looked upon as partners in providing health care to their children with Down syndrome. One mother stated:

> I'm the one who gives him his medicine, does his physio. I'm the one who drives him to all the appointments and keeps track of all the stuff. I am a major part of this. I think they (physicians) have to accept what I have to say too, that I can educate them also and I think that a team approach is effective.

These same mothers expressed the attitude that, although they were continually involved in their children's health care and liked to be treated as part of the care-giving team, they also realized that physicians didn't have all of the answers and that doctors were often faced with situations with which they have had little or no experience. These mothers realized that it was easy to judge physicians caught in such circumstances but that as users of physician services they had reflected on what it would be like to be on the other side of the treatment table. As one mother stated, "I think sometimes they're confronted with someone (a child

with a disability) they've never thought about before and don't know what to do and don't have any answers. It must be hard."

Although parenting a child with Down syndrome meant that the co-researcher had extra health concerns regarding these individuals, several mothers indicated that they felt they were fortunate compared to other mothers who had children more severely affected and who had to monitor stressful health problems such as seizure activity and respiratory dependency. One mother expressed this perspective saying, "My God, there are parents who live with kids who have seizures, whose kids have to be fed through tubes. In a way Down syndrome is not the worst case scenario."

In summary, mothers of children with Down syndrome had developed advocacy skills in the course of seeking health care for this child. This involved becoming informed of the child's condition, taking control over treatment decisions, and changing physicians if necessary. Networking with other mothers was a source of information, support and role modeling for mothers. Several mothers considered themselves primary health care providers who realized that physicians did not know all there was to know about Down syndrome These same mothers considered themselves more fortunate than other mothers of children with more severe disabilities.

Theme 3 - Co-researcher feelings about their experiences in obtaining health care for her child with Down syndrome.

All the mothers expressed a number of emotions when discussing their experiences in obtaining health care for their children with Down syndrome. Talking about certain aspects of their experiences with their children reduced several

mothers to tears during the initial and follow-up interviews. The hurt and grief experienced at the birth of a child with mental retardation and in the early childhood years was relived as these mothers told their stories. One mother stated," As you go through it year after year, you become more knowledgable, you become a little more outspoken, forceful, brave, daring but at the same time...I couldn't even express my feelings hardly, it just was hurting." Another mother described the cyclical nature of grief and how it impacted not only upon herself but upon the other members of her family. She said:

> The grief, the grief doesn't just stop at some point...It reoccurs, and it reoccurs for the sibs. I mean for J. (the older brother) to discover last year that F. will probably never be able to have a driver's license caused him to grieve and I mean cry really, really deep tears.

There were no fourth-order subthemes within this theme, however, feelings of anger and frustration were strongly present in three of the interview protocols. These co-researchers stated that anger was one of the feelings experienced at the birth of the child. One mother described her feelings shortly after the birth of her son as anger towards the child and God, saying,"I felt angry towards him (the child) because of course I was still grieving for the baby that wasn't. I did a lot of praying. A lot of yelling at God, more than what I would call real healing prayer." Feelings of anger were expressed by one mother over the lack of physicians' acceptance of parental input into treatment. She said,"Tell me how angry I am at the health care system. The generalization I'm trying to get to is that medical doctors feel that they are a closed shop." Another co-researcher described recurring feelings of anger when keeping appointments with physicians. She stated, "You

can't walk in (to the doctor's office) angry all the time and I think at different points I have."

Several mothers described circumstances when obtaining health care for their children resulted in intense frustration . Not being able to access services that they and other health professionals felt were essential for the child's well being was cause for such feelings. These mothers spoke of the difficulty of getting physician referrals for speech therapy and physiotherapy. One mother described her experience in this regard and the resulting feelings of guilt, in the following manner:

> The pediatrician does not believe that children with Down syndrome need physio. And he would not sign the referral forms to see a "physio". He's got himself convinced, therefore, if I wanted physio for N. I just had to go through another doctor to do it. The "physios" attached to the early education program certainly felt that he should have some. There were so many other things that I was coping with at the same time that, frankly, it never did get dealt with. I hope I haven't done him some permanent damage because I didn't get him any physio.

Another mother described her frustration at not being able to obtain treatment for a cold. She said:

> I can't tell you how many times I heard,"Well he has Down syndrome." I mean one of these times I am going to go, "Oh, he does?" It's absurd. Yes, he has Down syndrome but right now he has a cold, and yes I know that his eustacian tube is more horizontal than it is vertical. Yes I know why this is happening. Don't just throw your hands up in the air. I want some antibiotics.

The preceding examples also illlustrate instances when the mother had not been included as a member of the care-giving team. These co-researchers were the primary care providers for their children. Evidence from these interviews suggested that this role was intensified in these families. One mother felt very strongly at being thwarted in her attempts to obtain the best care possible for her son and at not being accepted as a valued member of her child's treatment team. She said:

> I get so frustrated with this. The frustration that they don't recognize you as a member of the team. You're not a member of the team. You don't know anything compared to them. And any suggestion you have to make, well, you're being impertinent if you so much as bring it up.

In summary, the co-researchers in this study indicated that they experienced feelings of grief, hurt, and anger at the birth of the child and for several years after the child was born. These feelings resurfaced when circumstances triggered those early memories or new situations emphasized the effect of the disability on the individual and his or her family. Most of the mothers also experienced feelings of frustration when they were not able to access services for their children because of physician opposition and when they were not considered part of the care-giving team.

Theme 4 - Helpful physician characteristics in obtaining health care for individuals with Down syndrome.

Considerable detail was provided in this thematic cluster due, in part, to considerable co-researcher interaction with a variety of physicians in the course of obtaining health care for their child with Down syndrome. In addition, at least one

physician was present during times of crisis and was the individual who assisted the mother in determining the health care and treatment needs of the child or adolescent. As their offspring with Down syndrome had related health problems and made frequent visits to physician offices and hospitals, especially in early childhood, these co-researchers regarded their relationship with physicians as an essential element in the provision of adequate health care for the child. As they relayed their experiences in obtaining health care for their sons or daughter, these mothers described physican characteristics that had been helpful to them in providing the care they were seeking. They also described behaviors that were instrumental in their decision to seek a second opinion or to change physicians completely.

Because the health care needs of these children often required the expertise of many physician specialists, the co-researchers discussed the necessity for and role of the primary care physician. This individual was the physician with whom they had the most interaction and with whom it was essential to have a workable relationship. For three of the mothers, this doctor was a pediatrician. For one mother the primary care physician was a family practitioner. Primary care physicians were viewed by these co-researchers as individuals whom they could choose from among a large group of practioners (i.e., who existed in sufficient numbers that enabled the mother to locate one with whom she could relate). This definition set these physicians apart from most specialists and subspecialists who did not exist in sufficient numbers that enabled mothers to be selective.

One fourth-order subtheme dominated the interview material on characteristics of the primary care physician. All co-researchers were unanimous in

their use of the term, "caring", to describe this individual. One mother stated, "We started out with very good doctors that cared, that seemed to be not only caring for her but also for us." When the mothers were probed to provide more detail and to elaborate on this term they concurred on four characteristics that described a caring physician. First, the co-researchers stated that the primary care physician was at ease with their child and interacted comfortably with their son or daughter. This physician displayed an overall attitude of acceptance of the patient. One mother described how the pediatrician would give her daughter a tickle that would make her giggle and then would ask her about the athletic activities that were very important to her. Another mother stated, "He's very warm and he plays little games with F. and he talks to him like he's a real person and he asks him questions and giggles with him and give me a high five and a low five and 'break the pickle' and he shows that he actually likes F." For some physicians this ability to put the child at ease extended to the mother and manifested as physician awareness of the mother's mental set. One mother described the pediatrician's particular manner with her in the following way:

> You go to see him and you feel depressed and exhausted and, God, what are we going to do, and tearing your hair out. You're not there ten minutes and you're laughing your head off from some silly thing. He knows that he had to lighten your mood before he can deal with you. Before he can tell you what needs to be done.

A second aspect of the caring physician was that he or she included the mother as part of the care-giving team and worked in a cooperative manner to help the mother to achieve her goals for her child, sometimes those outside the realm of

physical medicine (e.g., speech therapy, education). Being included as part of the team meant that the primary care physician validated her role as the primary care provider in the home. This validation was important to these mothers. One mother described the confidence and support displayed by the pediatrician once hospital treatment was discontinued when he said,"I think you can take better care of her at home, than having her lying in the hospital here. You just call me if there's anything that comes out of it." Another mother described her feelings at being included as part of the team. She said:

> It's nice to be made to feel like you're part of your son's team rather than the chauffeur, the person who drives him there. Because the thing is whatever they order, you're the one who makes sure it happens...It's real nice to be made to feel like you're part of the decision making process.

Still another mother described being overwhelmed by the empathetic manner in which a pediatrician responded to her request for speech therapy:

> The doctor said, "Well, if you need me to write a letter, whatever you need, I'll write a letter and I can be as nasty as you want. Like whatever you want from me I'm here to help". By this time I'm getting choked up and the doctor leaned over and he just kind of touched my leg and kind of patted it and said,"Look I'm here to help," he said, "You phone speech in ten days and there will be a referral there and something will happen. What else can I do for you?" And by this time I'm starting to cry. I said, "I don't very often get anybody offering their help. I'm usually begging for it and its real nice that I can leave here with my dignity intact also."

A third component of caring that was important to these mothers concerned the physician's skill in communicating with them. These mothers indicated that a caring physician was not only skilled in explaining treatment procedures to them but also listened to the mother's concerns. Caring physicians also displayed insight in determining what the mother's needs were as well as those of the child. They were quick to respond to the mother on a level at which she could relate. One mother described how one physician responded to her unspoken need for reassurance. She said:

> And the best thing that he gave me besides accurate information was that he gave me encouragement and he assured me that my instincts were sound and that I could do this. I could parent this child. And I think that's what all pediatricians need to do even if your kid's got the sniffles. It takes two seconds to say, "You're doing a good job, Mom."

All the co-researchers spoke of the concept of trust as a fourth characteristic of a caring physician. Here the co-researchers discussed the reciprocal respect that existed between themselves and the primary care physician. These mothers spoke of physicians who placed trust in their maternal ability to perceive changes in the health status of the child. Validating the mothers' concerns was important because of the limited ability of individuals with Down syndrome to indicate pain and discomfort. The following illustrates this point:

> I wouldn't go to a family doctor that was like that (not willing to listen to the mother). Our family doctor is really good. If I say something's not normal then he (pause)
>
> Interviewer: Listens to you?

I: Yes.

Interviewer: And he trusts your expertise?

Mom: Yes.

In turn the mothers expressed respect for physicians who were thorough and unhurried in their examinations and possessed an air of confidence and competence. One mother said, "They're very dedicated. Money is not the important thing or how many patients I (they) have on my (their) load doesn't seem to be important or how much time I (they) take, is not the important issue. They are just competent. They are sure of themselves."

A number of other characteristics were noted by the co-researchers as being important in their choice of primary care physicians. Several mothers noted that an empathetic and compassionate attitude was important and that the pediatrician they saw had a family member who was seriously ill or affected by mental retardation. Physician availability was noted by two of the mothers as being important especially during infancy and early childhood. This was the time when many problems manifested themselves and the mother was relatively inexperienced in coping with these difficulties. Similarly, physicians who were aware of the needs of the whole family, who took efforts to see that those needs were met, and who were knowledgable of community resources, were also valued by these mothers. One mother said, "The gynecologist and the pediatrician both were very caring and put us in touch with a family who was closely linked with the new (named) program. They wanted us to get all the help we could there." Several mothers mentioned the importance they placed on the physician treating the child like any

other child and not providing differential treatment for presenting symptoms because of the child's disability. One mother stated:

> There was no differentiation between having a handicapped child and having a regular child. They would do this kind of thing, I felt, for any kind of person. Because they were mentally handicapped they were not less, they weren't perceived as being less important, that they deserved every possible treatment or care that was needed.

In summary, the co-researchers stated that the primary care physicians with whom they interacted were caring individuals who were dedicated to providing competent care regardless of the intellectual status of the child. These physicians indicated that they liked being with the child, were interested in what the child was doing and were able to put the child at ease and interact meaningfully with him or her. They included the mother in decision making and validated her concerns for her son or daughter's health. They possessed good communication skills and set an atmosphere of mutual trust during consultations.

Theme 5 - How services have been delivered has been an important part of the co-researchers' experiences in obtaining health care.

Protocol data that focused on the availability of services and the experiences of the co-researchers in accessing services were grouped under this theme. One fourth-order subtheme emerged from the content analysis. All mothers agreed that they and physicians needed to work together cooperatively to provide adequate health care because individuals with Down syndrome had limited communication skills. This finding reinforced and amplified the physician characteristic theme of including the mother as part of the care-giving team as well as the co-researcher

behavior theme of advocating for services and doctor shopping. These mothers were unanimous in stating that the parent-physician relationship was essential when obtaining health care for their child with Down syndrome. The important caveat to that need was the deficit in adaptive behavior on the part of the child. Because he or she had a permanent difficulty in adequately understanding and communicating health problems, these mothers stated that they needed to act as an intermediary/liason between the child and the physician. The mother needed to be there as a health status interpreter. One mother described her fears should her son ever be in a position where no one was present to perform this function. She stated, "I guess sometimes when I think about him passing away, he'll probably die of something that no one bothers to recognize."

Similarly, several of the co-researchers spoke of the need to coordinate the services of the many physicians and health care personnel that were involved in their son or daughter's care and of the lifelong need for this kind of coordination. They expressed apprehension for the future when they would no longer be able to perform that function. One mother likened her role in the coordination of services to that of a ping pong player. She provided the following analogy:

> It's like they put the onus on you so you handle what you can and then you give it back to them and then they give it back to you. It's like Ping-Pong all the time. What's going to happen if something happens to me and there isn't someone to play Ping-Pong anymore for F. Is F. ever going to be able to do that for himself? I doubt it.

However, several mothers spoke of a solution to this problem in the presence of the pediatrician who could act as a coordinator of services and as a

point of reference for the mother. They suggested that the pediatrician, as the primary care physician, could make referrals, could explain tests and procedures and could assist in deciding what course of action should be taken once all the information had been gathered.

Three co-researchers discussed the provision of universal health care and what it meant to them. Several mothers spoke of the high level of medical care their child with Down syndrome had required and expressed appreciation for the national system of health care provided in Canada. They discussed the estimated costs for surgery and other procedures during the neonatal period and the financial burden such costs would have placed on the family. As one mother stated, "There are lots of families who would be put in a terrible position if they had to pay for all this." On the other hand, two mothers discussed negative consequences that they attributed to the method of fee scheduling and the necessity to cut back services due to reduced revenues. These mothers spoke of physicians being rushed and impersonal in their treatment because they could not take the time to become better acquainted with their patients. They also expressed concern that the system was rapidly becoming overburdened through over use due primarly to the spread of the HIV virus and the general aging of the population. As a result these co-researchers stated that services were getting harder to access and, from their perspective, the goals of universal health care were slowly being eroded. As one mother stated, "The health care system is supposed to help health care and make it accessible, make it affordable and all that stuff. I think they've forgotten that people are the end users and their system is not user friendly." Fears for the future were also expressed. This same mother said, "It's unfortunate that our health care system is a

business and the business is in trouble right now. And everybody's scrambling because what we have is chaos and everyone's afraid that there will be a breakdown."

In summary, when discussing how health care services were delivered to their child with Down syndrome, all co-researchers stated that a cooperative physician-mother relationship was essential for the provision of health care to their offspring with mental retardation because of the deficits in adaptive behavior characteristic of these individuals. Three mothers expressed their gratitude for the system of universal health care that had prevented the family from bearing an enormous financial burden. These mothers were also critical of the national health care scheme to which they attributed rushed physician behavior, impersonal service and inability to access services. They also expressed fears for the future of socialized medicine in Canada.

Theme 6 - Hospital experiences at the time of diagnosis of disability and later, have been varied.

All of the individuals with Down syndrome were born in hospitals and experienced subsequent hospitalizations during infancy and early childhood. No hospitalizations had occurred within the past year. The reader will recall that three of the individuals with Down syndrome lived with their birth families and one child lived with his foster family. The foster care began at four months of age and continued to the present, with the same family. While this mother did not experience the informing process at the birth of the child, she did describe being informed of a visual impairment. The birth mothers all had vivid memories of the hospitalization at the birth of the child and for the most part those recollections made

up the greater part of their experiences with the child in hospital situations. The child who was in foster care had been admitted to hospital on several occasions and the mother related those experiences and her impressions of care during those stays.

While all the children had experienced hospital stays, there were no common themes shared by all the mothers regarding hospitalizations after the birth experience. Several co-researchers commented on the stressful nature of hospital admissions both for the child and the mother. One co-researcher said:

> As soon as you go into a hospital you're more uptight. You're more under stress. You're more strained so you're going to be more snappy, more critical than sitting back at home drinking coffee and saying, "Oh yes everyone makes mistakes."

Another mother commented on the fear her child developed as a result of repeated hospitalizations in infancy and its effect on subsequent admissions. She said:

> As young as she was she had a good memory. She remembered a lot of things and so when we took her in the following year for a tonsillectomy, what a struggle we had to get her to the operating room.

All three birth mothers agreed that the birth of the infant and the accompanying diagnosis of Down syndrome was a time of trauma and personal crisis. Although no specific questions were asked, two of the co-researchers provided elaborate accounts of the birth experience and neonatal period. These mothers regarded the birth of the child with Down syndrome as the most significant event in their lives and were able to recount events in great detail. The third birth mother focused her remarks on the health care professionals who provided care

during that period of time and did not elaborate on the details of the informing process or her feelings during that time. As the focus of this study was one of experiences in obtaining health care and not the birth or parenting experience, probing was done to elaborate on professional behavior and management of that aspect of the birth experience.

While being informed that one's newborn has Down syndrome is usually shocking news for parents, it is likely that initial responses are as unique as the individual respondents. One mother described it as an earth shattering event that changed her life forever. "I've fallen through a trap door," she said, "into another world and I can never get out of it." In spite of these feelings, this mother gave credit to the pediatrician who presented the information in a straight forward yet compassionate manner. His remarks became even more credible when he revealed that he was also the father of a child affected by mental retardation. She said, "I liked the fact that when I was informed by him that N. had Down syndrome, he was straight on about it and I liked the fact that he also had a child who was affected with a similar kind of thing." A similar experience was relayed by another co-researcher who stated that from the time of her daughter's birth, hospital care had been provided by "a whole team that sort of work together at the hospital and they are very caring and very understanding." Both of these mothers spoke highly of the nursing care they and the infant received. One mother described how the nurses "took a lot of time to come and talk and help," and that they "tried to give us as much help as possible, where to go or what to expect, and they also wanted that support in the community." For both these mothers, community supports in the

form of early intervention services and a visit from a member of a family support group were initiated by hospital personnel.

The birth experience for the third mother was completely different. The pregnancy had been marked by threatened abortions, numerous ultrasonography tests, and a move to another city. After the last of these tests was performed, the mother knew the infant she was carrying was affected by Down syndrome but she was repeatedly frustrated in her attempts to get more information. She said:

> But again nobody talked to me about the baby. I think when you are threatening to abort nobody wants to talk to you about the baby and that's what you most want to talk about. And you know they left me sitting in the hallway, in a wheelchair, crying. Nobody would talk to me about Down syndrome.

Contrary to the birth experiences of the other two mothers, this mother was not informed of community services, was given no hope for her infant and was encouraged to place the infant into foster care. She described the informing process in the following way:

> (They said) you know this child isn't going to care who meets his needs as long as they're met and they'll be few. By the head circumference they felt that he would really be severely mentally handicapped and that he would never toilet train and our (older) son would grow up to hate us because he would be such a burden and our marriage would disintegrate and basically they took away the rest of our hope.

The mother also described how she was not allowed to touch or hold her infant after the birth and that no one came to talk to them about what had happened or

what their choices might be. She said, "they (hospital staff) wheeled us down the hallway, put us in a private room right across from the nursing station, put a "no visitors" sign on the door. But half an hour later they wheeled a cot in for my husband and they brought a sleeping pill. Nobody came."

The co-researcher who was a foster mother spoke of being informed of her son's visual impairment in a manner that did not take into account her feelings. Although her son was four months old when the child was placed in her home, she was not aware of the visual impairment until some time later. She described the informing process this way:

> And he (the physician) goes, "I think he's blind in both eyes. He can't see anything." I remember just crying my eyes out coming home... I guess I'm really visual. I was thinking that he'll never see his mother's face. It blew me away. But he (the physician) was pretty cold and not too worried about us, I think.

In summary, what is apparent from the data is that, while the child had experienced hospitalizations subsequent to their birth, it was that initial experience that dominated the interview material for the birth mothers. These mothers indicated that the informing process was painful and traumatic but that compassionate and caring hospital staff lessened those feelings, and gave the mother hope for the child's development and practical guidance for the child's care This did not occur if informing physicians left the mother with no hope for the infant's development, if the mother was not encouraged to provide in-hospital care for the infant and if home care for the infant was not encouraged.

Theme 7 - Societal issues regarding treatment and care of individuals with Down syndrome.

All co-researchers discussed a number of concerns that reflected the global issue of limited societal preparedness to provide services to individuals affected by Down syndrome or other forms of mental retardation. While the reflections of these mothers emanated from their experiences in obtaining health care for their offspring with Down syndrome their concerns extended into many facets of their child's life.

The most significant subtheme here centred around differing attitudes towards mental retardation that the co-researchers had experienced when obtaining health and related care for their children with Down Syndrome. Three mothers gave examples of physician behavior that they interpreted as a lack of valuing their child. One mother told of a physician who referred to her son using the third person subject pronoun used to describe objects. She said, "He referred to F. as an it and told me that (a relative) had one of those and that it should be in an institution." Another mother who had sought treatment for a heart condition for two of her sons, one of whom was affected by Down syndrome, described what she perceived as differing attitudes towards treatment on the part of attending physicians. She said, "The interesting thing to me was when we took O. (the child with Down syndrome), her (the physician) first question was , "Do you want to save him?" She never asked that for K. On another occasion this mother stated, "It just seemed to us that compared to our other boys, there were some (physicians) whose attitude was, 'why bother? Why bother taking care of him? We'll just do the bare minimum.' " Another mother related physician statements regarding

prescribing Synthroid for a thyroid condition and resulting fatigue that her daughter was experiencing. She said:

> Dr. U. said a lot of doctors would just shut off and not do anything. They feel, "Oh well, so what if they're (child with Down syndrome) fatigued or so on, there's no problem, just let them go." He says, "I don't believe in that. I believe in giving them the best possible chance there is."

This same mother described an incident in which she experienced physician behavior that ran contrary to that which she had been accustomed. She described the following scene:

> When Dr. N. was away one day and we had taken her in for an appointment she was crying her heart out and the other doctor finally took her ahead of some of the others and he just yelled at me when he got in the office. He said, "Why in the hell did you have her to start with?" Oh he was absolutely nasty. His attitude was exactly the opposite to what we had experienced and I think he would have been the same probably with any other child with special needs.

Because other physicians had repeatedly modelled behavior contrary to what she experienced on that particular occasion, this mother was able to accept the incident as indicative of exceptional behavior rather than the norm. However, repeated exposure to similar behavior on the part of physicians questioned the parental role in caring for the child and was painful to the mother who loved the child unconditionally. One co-researcher described the feelings of hurt she experienced after such occasions. She said, "Sometimes it just amazes me and I

think it's funny. But I have this sort of sick feeling in here. And other times it just cuts me to the core, driving home from the (clinic), crying my eyes out."

Three co-researchers commented on the visit by the public health nurse following the birth of the child. While these mothers felt that the goals of the public nurse were likely accomplished during the interview, it was evident that the nurse had limited familiarity with Down syndrome and was not able to assist the mother in such things as coping with the special needs of the child, and locating services. One mother felt that the nurse's comments did not reinforce the information she had received at the hospital. She said, "I just feel that they were not in tune with what was happening and not in tune with the line of people we had been working with." One mother had experienced two visits from the public health nurse, after the birth of each child, one of whom was affected by Down syndrome. After reflecting on these visits, this mother suggested that expectations for the public health nurse to have detailed information about Down syndrome were unrealistic and that a more logical way to provide the added need for service and information that these mothers have, might be as hospital outreach. She said:

> I know the public health nurses are supposed to be the outreach but there are extenuating circumstances with special needs children as far as I'm concerned that would save the children and the families a lot of grief if it was more hospital based as an outreach service, something like that.

While three of the co-researchers expressed concerns for the valuing of their offspring with Down syndrome, one mother struggled with the moral issue of allowing infants with Down syndrome to survive at birth in the light of an already overburdened health care system. In addition, her own familial principles that

placed high value on intelligence were contrary to maintaining an infant affected by Down syndrome. For her, placement in a setting outside the family home after birth, was not an option she could consider as it represented for her a double standard that was unacceptable. From this mother's perspective, an accusing finger was pointed at the birth mother while the foster mother was treated as a heroine. It was, "as if the woman who produces him is bad, but the woman who adopts him, who's doing exactly the same thing is a heroine." She accepted responsibility for the infant and expressed the view that active euthanasia should be an option available to parents at the birth of an infant with Down syndrome. From her world view, it was illogical to preserve the life of infants who were "damaged". She described the contradiction she witnessed in legislation that allowed abortion of fetuses with Down syndrome but condemned active euthanasia a number of weeks later. She said, "And it all starts with the choice at the very beginning and at the moment it's not a choice, it's murder. And yet seventeen weeks earlier if I had had an abortion, "Thank goodness, she had an abortion. Her baby would have had Down syndrome." This mother reconciled the dilemna she experienced by stating that if parents were not allowed a complete range of treatment options at the birth of a child with Down syndrome, then society had an obligation to provide the funding for the whole range of health related services that would be required by the family in parenting the child. This view, societal provision of funding for lifelong health care supports of infants with congenital abnormalities such as Down syndrome, was echoed by two other co-researchers. Another mother stated:

> It's a big heroic thing to save kids...If you save them then you have got to look after them all the rest of the years with all the things they come in with,

> and they are going to come in with measles and mumps and all the other reactions and diseases that you get, or else don't save them at all. I think the decision has to be made really early what's going to be happening.

Societal responsibility for saving and supporting these individuals physically also extended to family support. All co-researchers spoke of the importance of community support for the family beginning with early intervention programs that were designed to assist parents in maximizing their child's developmental progress and in coping with the emotional and pschological aspects of living with a child with mental retardation. Such support, repeated several mothers, was a form of preventive medicine, providing parents with information and coping strategies that empowered them to seek out the best services for their child. One mother described the role that early intervention and other support programs played in the parenting process in the following way:

> That kind of program, despite the fact people treat it as a side issue because it's not out and out heart surgery, is where the parents begin to cope, if they're going to, and by and large they probably will be able to if they have that kind of support.

In summary, the co-researchers expressed concerns regarding varying physician attitudes towards their child and towards societal committment to providing the necessary "cradle to grave" services that they felt were necessary to support the infant and his or her family through the developmental process. They suggested that society needed to look carefully at contradictory attitudes that heroically sustained these infants at birth but were ambivalent about extending that level of care over the life span.

Analysis of responses to the question, "What has been most helpful to you when obtaining health care for your son or daughter affected by mental retardation.

In addition to being asked to recall their experiences in obtaining health care for their offspring with mental retardation, the co-researchers were asked to comment on what had been most helpful to them during these experiences. Responses to this question focused on the system of socialized medicine and the supportive role played by individuals with whom the mothers had contact. While there were no fourth-order subthemes, three mothers, including the foster mother, agreed that having access to a caring, understanding physician who included them as part of the care-giving theme, had been most helpful for them. One mother stated, "I guess it would be a good understanding attitude from the doctor. Another mother said, "When you do hit a health care professional who really does listen and is willing to try and accept you as a member of the team, that helps a great deal." For the other co-researcher, it was the support provided by other mothers in similar circumstances that had been most helpful. She said, "When you have a child with a disability, in order to survive you need a network of other moms who have kids with disabilities. It's the moms along the way that have helped the most."

One second-order subtheme emerged from this thematic cluster. Two mothers stated that the publicly funded health care scheme they accessed for health care services was most helpful because it eliminated the worry of having to personally pay for essential but expensive health care services. Having to pay out of pocket for heart surgery, for example, would have increased the stress level of a family already in crisis over the birth of a child with Down Syndrome. It was also

likely to affect the decision to keep the child in the family home. As one mother stated:

> The first and most important thing is, God help us if we ever give up socialized health care. The implications for our own kids and families are very serious. There are lots of families who would be put in a terrible position if they had to pay for all this.

For these mothers the elimination of the financial burden was an important factor in their experience with obtaining health care for their child. Of even greater importance, it would seem, was the understanding and support of individuals along the way who had eased the burden of worry and stress that accompanied these experiences.

In summary, the content analysis illuminated seven themes that were held in common by the four co-researchers of children with Down syndrome. These mothers revealed that their offspring with Down syndrome had associated health problems, had required heart surgery in the neo-natal or early infancy period but were relatively healthy at the time of the interviews. There were a number of personal characteristics that these mothers shared as a result of their experiences in obtaining health care for their child. They had learned to become advocates for their child with mental retardation and sought physicians who included them as part of the care-giving team. They changed physicians if necessary in order to have some control in their child's health care treatment. These mothers networked with mothers in similar circumstances to gain information and support. Anger, hurt and frustration were the emotions these mothers had experienced at the birth and diagnosis of the child and in later years when obtaining health care for their child.

The co-researchers described helpful physicians as caring individuals; who were comfortable in interacting with both the mother and the child, who possessed good communciation skills, who included the mother as part of the care-giving team to help her achieve her goals and who set an atmosphere of mutual trust at appointments. While the mothers expressed appreciation for the presence of a universal health care scheme, they had experienced some problems with discovering and coordinating the many services that their child required. The necessity for cooperation between parent and professionals to organize and coordinate these services was stressed. While hospital experiences at the birth of the child varied, all mothers agreed that the time of birth and diagnosis was a traumatic event for them. Several mothers agreed that nurses provided good care and sound advice if realistic expectations were set for nurse availability and knowledge. Several issues surrounding societal attitudes regarding the care and treatment of individuals with Down syndrome were elicited. The mothers agreed that societal valuing of individuals with Down syndrome needed to be accompanied by a continuum of services available throughout the life span. When these mothers reflected on what had been most helpful to them when obtaining health care for their offspring with Down syndrome, they agreed that it was individuals who had been supportive of them and their child that have helped them the most.

While these co-researchers shared a number of themes in common with their counterparts who had offspring severely affected, there were differences in the specific details that comprised these themes. An additional theme cluster also emerged from the content analysis of the interview protocols of the co-researchers

in the severe group. The within-group analysis of the mothers of individuals affected by severe mental retardation will be discussed next.

Mothers of Children with Severe Mental Retardation

Eight thematic clusters emerged from the analysis of the interview data for this group of mothers. Fourth-order subthemes emerged in five of these themes. Overall, the experiences in obtaining health care for the children described by this group of mothers represented a more diverse perspective than that described by the mothers of children with Down syndrome. This is due in part to the fact that Down syndrome is relatively easy to diagnose, diagnosis takes place at birth or shortly thereafter, and the anomalies associated with the syndrome manifest themselves similarly. The children in the group with severe retardation experienced diverse and recurring health problems, throughout their childhood and adolescence, some of which had life threatening consequences. This factor influenced the experiences related by these co-researchers and the themes that subsequently emerged during the content analysis.

Theme 1 - Child characteristics that necessitated health care.

Four fourth-order subthemes emerged in this theme revealing a child with diverse characteristics and health related conditions. The first theme concerned manifestation of the condition. Whereas the diagnosis of Down syndrome was made at birth or shortly thereafter, the multiple conditions displayed by the individuals in this group were not immediately apparent at birth and were revealed gradually when the infant either failed to reach developmental milestones at appropriate times or developed a condition after the neonatal period that caused a regression in developmental gains. As one mother said, "As far as I knew, the only

thing wrong with him was that he couldn't really roll over so I thought that it was just a physical thing." Another mother described how the child's behavior was indicative of normal development until he experienced a seizure at six months of age.

The full extent of the disabling condition experienced by these individuals was also revealed gradually. For example, while the diagnosis of severe neurological impairment was given to one infant at nine months of age, the ongoing seizure activity that contributed to that condition was not diagnosed and treated until the infant was eighteen months old. Another child's global developmental delay was labelled as autism when he was almost four years of age. While the disability was not evident at birth and revealed itself gradually, the actual diagnosis for the condition was also difficult to obtain and involved seeing a number of physician specialists over a period of time. In one case an initial diagnosis was changed after more information on a rare genetic disorder was obtained. Another mother reported on the lack of a definitive diagnosis for her three and a half year old child by saying, "He's developmentally delayed, mild CP (Cerebral Palsy) I guess, and a seizure disorder. So you know, you kind of take your pick."

The children in this group all required constant supervision either because of their total dependency on others for their personal care needs or because their level of activity and understanding was such that they could endanger themselves if they were not monitored. As one mother stated:

> This kid needs supervision all the time because he's active. He's into everything. He doesn't understand. He loves the water. He loves crawling. He destroys everything. So you just can't leave the room. You

have to always keep an eye on him. I'm not saying he's bad the whole time but you can't leave him alone.

While three of the children displayed some independence in feeding themselves, all the mothers reported that their offspring with mental retardation required monitoring or assistance during mealtime. This was due to the fact that the child either did not have the motoric ability to feed himself/herself, failed to chew his or her food adequately, or lacked the understanding of how much food could be eaten at one time. As one mother stated:

He eats everything we do. He mostly tongues it on the roof of his mouth. He is starting to move some food around and we're getting him to eat sandwiches now. So we get him to take a bite, a small bite. You've got to be careful because he will try to cram the whole thing in.

Lack of independence was also manifested in the reduced ability to communicate personal needs that was experienced by the child. One child had some capacity for speech while the other three individuals, described by their mothers, used very basic sound or gestural methods of communication. As noted by one mother, this characteristic impacted upon her ability to understand her son and was cause for considerable frustration on her part. She said:

One of the most difficult things with him is when he is unhappy, crying or miserable, trying to figure out what is wrong because he doesn't talk. That is always the way it is. Just trying to figure out what's wrong with him.

The co-researchers also stated that their child with a severe disability experienced additional problems apart from the eating and communication difficulties, some of which had health related consequences. One child required

assistance with mobility while another used a wheelchair. One child had a hearing impairment and displayed aggressive and self-destructive behaviors. Three individuals experienced seizure activity that was partially controlled by drugs. One mother likened her son's condition to that of a chronically ill child, with symptoms that kept recurring. She said it's "like tonsils, you get your tonsils out, you're better. You're fine. You go home and you never have a problem again. D's problems just seem to be coming back and back and reoccuring, more like chronically, on-going problems."

In spite of these additional problems, several mothers stated that compared to the infancy period when the child's health was unstable and new conditions were appearing, their child was relatively healthy now. However, they went on to describe the kinds of physical and psychological adaptations to care that they had developed. One mother described her behavior in the following manner:

> But things have got better for him. They're still bad but there still has been an improvement. He used to be in the hospital every two or three months until this year. We took flu shots, maintenance antibiotics. We did everything we could think of to prevent him from getting sick. Ran the croup tent every night whether he needed it or not and I have two things that take the dust out of the air. I "pinesol" (a disinfectant) his walls, his bed, everything every second day.

For another mother, the state of good health her daughter generally had experienced in recent years was relative to an overall state of fragile health due to the extensive neurological damage her daughter sustained in utero. For this mother, health problems related to her daughters' multiple disabilities and seizure disorder

resulted in a number of serious health threats for which there was little or no help. She stated, "the kinds of health problems she does have are so unsolvable that I'm just left to fall back on my own resources for the most part."

In summary the children in this group exhibited multiple and chronic problems necessitating health care that were not apparent at birth but were manifested gradually during early infancy. The children were dependent upon their mother for assistance in eating, for monitoring all daily activities and for interpreting communicative intent.

Theme 2 - Co-researcher characteristics and behavior that assisted them in obtaining health care for their children with severe mental retardation.

Like their counterparts in the group having offspring with Down syndrome, these mothers had developed advocacy skills in order to obtain services and equipment for their children with severe mental retardation. They reported being assertive in interactions with physicians and nurses as well as other health care professionals such as physiotherapists. One mother stated:

> But I'm much more assertive now. A nurse was trying to tell me, "Well maybe you should see how he does." and I just said, "Look, I want an appointment and I want one today." They managed to fit me in. I don't let them push me around anymore.

The benefits of networking with other mothers in similar circumstances was also stated by the co-researchers in this group. For one mother, the opportunity to share with other parents in an organized support group gave her confidence in caring for her son. For another, contacting a support group organized for the purpose of gaining and sharing information regarding a rare condition, resulted in a

confirmed diagnosis for her son's symptoms. At times these mothers took extraordinary measures to assist each other in obtaining accurate and helpful information. One mother described how she obtained information that led to a diagnosis of her son's condition. She stated:

> I met a mother who also met my son and she lives in D. That's where the research is going on right now. And she listened to a doctor talking on ( ) syndrome. She heard this and she recognized that that's my son. So she got all the information she could and she actually came down and gave it to me. As I sat there and read it, I kept saying to myself no, no, no. Then I went back to the geneticist and said, "I think this is what he has." Sure enough he agreed.

Developing advocacy skills and sharing information with other mothers in similar circumstances empowered these mothers and enabled them to take control over their child's health care and treatment. For some mothers this meant that they were able to obtain treatment for their child quickly, or sought a second opinion when they disagreed with a physician's diagnosis or treatment decision. As one mother stated, "We always thought that the doctor knows best. And then we decided that, no, we know best. They're not doing any good for him." The doctor-shopping behavior described by the mothers of individuals with Down syndrome was also found among mothers of individuals with more severe disabling conditions. The mothers in this group stated that they changed doctors in order to obtain a second opinion, especially if they disagreed with the first one. Not willing to accept a diagnosis of severe mental retardation, three of these mothers sought opinions from another physician. One mother described her experience this way:

> By the time H. (her husband) and I felt confident enough that okay, we don't think that Dr. T. and Dr. H are doing anything more for E. (her child). What they basically told us the last time we saw them was, "Love your son. He's severely mentally retarded. He's never going to amount to anything. That's that." So H. and I decided, "Well, we don't agree with you and we think we're entitled to a second opinion."

Another mother described this behavior as "doctor hopping" in which she sought opinions of different physicians and specialists in an effort to find someone who would agree with her that somehow her daughter could be "fixed". This behavior suggested that these co-researchers would not accept a diagnosis that allowed them no hope for the child. Such a diagnosis made early in infancy or early childhood would have made the burden of care intolerable. Therefore, they searched for a physician who did not paint a bleak future for their child. One mother described her situation in the following manner:

> H. (the husband) and I aren't deluding ourselves that our son is one day going to wake up and say, "Hi Mom and Dad." I know he's not ever going to be "normal" but to have somebody tell us that he'll never reach any degree of independence would be terribly crushing and it would make all the work now even harder to do because when you don't have any hope. And maybe that's why some doctors just say, "Hang in there."

Like the mothers in the Down syndrome group, these mothers wanted to be considered a member of the treatment team and expressed a need to be part of the decision making process. One mother spoke of her relationship with a pediatrician who "believes in the parent" and who supported her in her decision to seek a

second opinion in another city. A different experience was described by a mother whose request for material to inform herself of her son's condition was met with opposition by the attending physician. Another mother compared the early intervention program approach of parental input into the assessment and educational planning process to that of a health clinic approach to health care assessment and planning. She said:

> When they do these IEPs with the kids, I can go to school and I can actually take part in a conference. When you go to the H (the clinic) you don't hear what the conference says because they talk about your child and you're not there. They send you a letter. You don't get much say in the whole matter.

In spite of the fact that several of these mothers changed physicians to obtain a second opinion of the diagnosis, they were not critical of physician behavior. Several co-researchers stated that physicians could not know everything about their child's condition. One mother said, "It's certainly easy to dump on doctors and I don't think it's all that productive." Another mother began to set realistic expectations for physicians once she herself had become more informed. She said, "I realize that doctors don't have all the answers."

In summary these mothers had developed assertive behaviors that enabled them to advocate for their offspring with severe mental retardation. They shared information with other mothers that helped them to become informed of their child's condition and that enabled them to take control of their child's treatment. These mothers changed physicians if they did not agree with a physician's treatment

decisions, if they did not feel that they were included as a member of the treatment team, and if they were left with no hope for their child's development.

Theme 3 - Co-researcher's feelings regarding experiences in obtaining health care.

Mothers of individuals with severe mental retardation shared similar feelings with mothers of children with Down syndrome regarding their experiences in obtaining health care for these children. These mothers, too, when reliving diagnosis and treatment events, demonstrated that these recollections were painful and that the extensive problems they faced in providing care for their offspring with mental retardation were often overwhelming. It was also apparent that grief over the absence of normal development was part of the pain these mothers experienced. One mother expressed the recurrence of grief that she experienced as a healthy coping mechanism. She said, "I don't say, 'Well this is my day to grieve,' or anything like that, but I think it's healthy because it means that you're dealing with things and taking about them."

Anger and frustration were experienced by all co-researchers in this group. The mothers of children with severe disabilities expressed anger at some aspect of the health care system or some individual who provided treatment or care. For several mothers inequitable treatment because of disability was a shared perception. One mother described her behavior after angrily expressing her concerns to hospital staff over the waiting time for tests, in the following manner:

> Then I went to my room and I felt like a fool. And I cried. I said, "This is ridiculous. I said to another mother in the same room, "I'm not angry at you. This is what happens to all parents of disabled kids. We get put on

> the back burner all the time." I said, "I'm not mad at you. I'm mad at the system."

Similarly, another mother expressed anger at discovering that her distraught son had been left unattended in his darkened hospital room for long periods of time. For both these mothers inequitable treatment because of disability was a shared perception. Finally, another mother described the prolonged anger that she experienced over the diagnosis given her daughter and the manner in which it was delivered. She stated, "I think perhaps because of the way it was presented, perhaps because I felt so powerless that it (the diagnosis of severe neurological impairment) left me predominantly very angry for many years and very rebellious and wanting to somehow make it right, to somehow fix her."

In addition to anger, these mothers also related incidents where they experienced frustration especially over the difficulty in obtaining services or equipment. One mother described the frustration she felt over the waiting time for an important diagnostic test. She said:

> E. should also have an MRI which is a magnetic resonance whatever. He's been on the waiting list for that for a year. And that really upsets me because if there was anything to be found out, and you know as E. gets older, it's getting harder, so I guess that really bothers me because he hasn't had that test done and we've checked several times and we keep getting told that he's on the waiting list.

Frustration over the time and effort required to obtain a diagnosis was also experienced by several mothers. These mothers described circumstances in which they knew that the child's behavior and lack of developmental progress was

indicative of physiological disorder but their efforts to alert physicians went unheeded. In spite of these efforts, three of the mothers experienced feelings of guilt over not obtaining a diagnosis sooner One mother described her feelings this way:

> There was all those questions in the back of my mind and to this day thinking, "Well maybe he'd be a little bit more advanced if his brain was fed properly for eight months." And then you get the guilt. Like, "I should have known better. I shouldn't have waited eight months trusting one doctor." But you can't. That's the way it is. You learn.

These mothers expressed having feelings of guilt over other aspects of their child's health care. One mother expressed guilt over being the individual who administered powerful anticonvulsant medication to her son. While such medication was necessary to prevent further damage to brain tissue, many of these drugs have serious side effects which posed a threat to other organs and body tissues if taken for extended periods of time. She stated, "I sometimes drive myself crazy thinking, "Am I killing him slowly, very, very slowly?" Another mother noted that had she been able to feed her daughter more than three times a day, the child might have regurgitated less and had fewer seizures.

The mothers of the two preschool children stated that they worried over their child's present condition and future development. One mother stated, "I worry about what the drugs are going to do to his liver. That's one of my biggest fears and I also worry about what he will be like when he grows up." The other mother expressed general anxiety over her son's condition that required frequent hospitalizations and considerable effort in the home. In addition she expressed

concern over the effect her son's unstable condition had on her older child who was beginning to display behavior indicative of adjustment difficulties.

In summary, these mothers expressed feelings of anger and frustration, related to the inequities that they perceived in the provision of health care to their child with a disability. Anger at lengthy waiting lists for tests and over diagnosis issues was described. Expressions of guilt and worry over their child's future also comprised a sub-theme described by several mothers in this group.

Theme 4 - Helpful physician characteristics in obtaining health care for individuals with severe mental retardation.

In a manner similar to the mothers in the Down syndrome group, these mothers spoke of physician characteristics that were helpful in assisting them in their care-giving role. Again, helpful physicians were described by all the co-researchers (i.e., it was a fourth-order subtheme) as caring individuals who were concerned for the health of the child, the mother and the family. As one mother stated, "He sees our family as a family. He doesn't just see B. and her handicap and her sponsors. He sees a family and he treats us like a family with some difficult issues to deal with, not like a handicapped family." For these mothers this physician was either a family practitioner or a pediatrician The caring attitude these mothers described was perceived as extending beyond a clinical interest and included empathy and compassion for the mother's concerns. For one mother the relationship with the pediatrician had been established over a period of years in which they had experienced many crisis situations together. This had resulted in physician awareness of her particular family circumstances and his knowledge of

her concerns. As a result, when both mother and child were hospitalized, he would personally give her daily reports of how her son was progressing.

Caring physicians also respected the mother's concerns and expertise and included her as part of the care-giving team. For one mother this meant that the physician went out of his way to explain test results so that she and her husband would have a better understanding of the effects of particular drugs on their son's blood levels and behavior. Several mothers spoke of physicians who validated their concerns and who built up their confidence in providing care for their child and who praised their son's or daughter's progress. These mothers indicated that helpful physicians gave them hope that the child would make some progress and that such a stance was necessary if they were to continue caring for the child in the family home.

Helpful physicians also were knowledgable of community resources and helped the mother access those resources. For one mother, information obtained from a physician concerning services that were available for parents of children with disabilities was the first indication that she was not alone in her struggle to parent her child but that, by providing these services, society was validating her role. This realization was paramount for this mother and represented a turning point in her behavior. She stated, "It was a sudden moment of recognizing that I wasn't alone, that society was sharing this with me. And in fact what I was doing was perceived as valuable by society."

Because individuals with severe mental retardation often have serious health problems such as seizure activity, it was important for several of these mothers to have primary care physicians who were informed of the latest developments in the

treatment of the conditions their son or daughter experienced, that they were thorough in their examinations and that they used all available resources before coming to any conclusions. Like the mothers of children with Down syndrome, these co-researchers were interested in knowing as much as possible about their children's condition and sought to be informed by reading whatever material they could find on the symptoms their child exhibited. They expected no less of physicians who cared for their child. One mother described this behavior in the following anecdote:

> We spent about an hour with Dr. T. and we felt more positive and hopeful than we had since this all started. I guess just because he's more of a happening type of person. He's not just going to look at a child and say, "This child is mentally retarded. Love him and don't worry about it." He (Dr. T.) said, "When I look at E. it doesn't look like he should have all these problems. So there has got to be something we're missing so let's get all this done."

Unlike the mothers of children with Down syndrome, these mothers were less concerned about coordinating care than with finding a physician with whom they could relate. Several mothers indicated that they had experienced arrogant attitudes among some physicians who gave the impression that they were on "an ego trip," and would not refer the mother to another physician if they could not solve a problem in a manner that was satisfactory to the mother. When this happened these mothers switched physicians. One mother described her experience in the following manner:

> I went through a couple more pediatricians and I found one who listens, who's concerned, who cares. I've been going to him ever since and he's been good. He's not a doctor who is on an ego trip and he knows all the answers. He is the first to say, "I don't know." He will send you on, which is the way it should be.

In summary, these mothers were grateful to find a physician who cared for themselves and their children and who validated their concerns. Helpful physicians were individuals who cared for the child and his or her mother and included the mother as part of the care-giving team. They were competent physicians who were informed of the latest research and were challenged by the child's conditon. They were knowledgable of community resources, gave the parents hope that their child would make developmental gains and expressed confidence in their ability to care for the child.

Theme 5 - Co-researcher's experiences when hospitalization was required for the child with severe mental retardation.

Several fourth-order subthemes emerged under this theme. As each of the mothers had experienced the hospitalization of her child with the disability within the past year, it was likely that the memories of that experience were quite vivid, easing her articulation of the details. Unlike the mothers of the children with Down syndrome, hospitalization at the birth of the child was not mentioned by any of the co-researchers in the severe group. This was likely due to the latent manifestation of symptoms and diagnosis subsequent to demonstration of problems, all of which occurred after the neonatal period. For all the co-researchers, the children were hospitalized at least once before a diagnosis was made and numerous times

subsequent to diagnosis. It was these hospitalizations and subsequent visits that made up the experiences that the mothers recalled and described.

Two fourth-order subthemes emerged from the interview analysis. All co-researchers agreed that, for the most part, hospital staffing schedules and routines could not adequately meet their children's needs. There just weren't enough nurses available to provide the need for constant supervision, careful observation and detailed charting that was required to monitor conditions such as seizure activity that had necessitated the hospitalization. One mother described the situation on the ward when her son was hospitalized to establish a seizure pattern. She said:

> They were supposed to record every time E. had a seizure. And H.(her husband) or I were with him 24 hours a day. If we wouldn't have been with him, they wouldn't have known when he had a seizure. You know they just run in and out. Kids were crying all the time.

All the mothers noted that it was only by being in constant attendance that they were able to accomplish at least some of the goals of the hospitalization. The mothers stated that when their son or daughter was hospitalized they kept a vigil in the hospital, providing most of the care themselves. In this way they could also monitor the children's schedule and ensure that the children's routines were maintained. Constant attendance on their part also maximized the opportunities of meeting with physicians who were difficult to access. Such behavior on the part of the mother also served to eliminate fears that a lack of nurse or physician familiarity with individuals with severe retardation could result in crisis situations. Familiarity with hospital routines led the majority of mothers to agree that it was unrealistic to

expect nursing staff to have a working knowledge of the specific aspects of their son's or daughter's behavior. One mother stated:

> We're talking about a child with very severe, complex unpredictable needs and we're talking about a "bare bones" sytem of nursing evaluation because of cutbacks, etc. But I suspect that even if there weren't cutbacks it wouldn't make all that much difference because nurses are not trained in this way. They have to know a lot of things but they don't necessarily know the subtle ways in which a severely handicapped child seizures, etc.

Several mothers spoke of the willingness of nurses to share information, and the important function that served for them. Another mother noted that her attitude and behavior toward her daughter in hospital provided a model for staff. She stated, "I have felt a lot of respect from physicians and nurses in the hospital...They see that I am stubborn and I'm going to sit there and I'm not going to leave her and when they see that kind of commitment they respond very positively."

In summary, the co-researchers with children who exhibited severe mental retardation stated that hospital staffing and routines could not adequately accommodate the intense needs exhibited by their sons or daughter. In order to ensure that her child was adequately cared for in hospital, the mother or some individual other than hospital staff was in constant attendance to monitor care, maintain the child's routines and to assist in treatment.

<u>Theme 6 - How services have been delivered has been an important part of the mothers'experiences in obtaining health care for their children with severe mental retardation.</u>

While all of the co-researchers discussed various aspects of the way health care services were provided, there was less consensus among these mothers as to how they had experienced service provision. This was likely due to the uniqueness of each child's condition and the differing nature of the services they needed. In addition, some of the issues discussed by these mothers were suggestions for improvements in providing a wide variety of services, not just those related to health care, that were required by families of children with severe mental retardation.

While three co-researchers indicated that they could access many services that they required to meet the health care needs of their children, they also indicated that it took time for them to find out about these services. In addition, once they were informed of the service they often discovered that they were at the bottom of a long waiting list. One mother said:

> We've had, of course, to wait longer for different appointments like, for instance, to get into the (clinic), I think it was seven months that it took to get into that. Dr. S. mentioned it three months after we started this with E. and it was close to a year before we could even get into the (program) or even get an assessment. So it just seems like the help is out there but you have to wait too long.

These mothers also stated that the waiting for services was worrisome especially if the mother viewed it as promoting even more developmental delay than the child was already experiencing. Another mother spoke of the time required to receive specialized equipment if the appropriate channels were used for approval and ordering. By directly intervening in the order process, one particular family was

able to receive the equipment in a fraction of the time normally required. However, such action on the part of the mother or father was viewed as time consuming and stressful, especially if such action was continually being required.

While many services were available, accessing them could be accompanied by practical difficulties. One mother described missing physiotherapy sessions for her daughter with a disability because she had two other preschool children at home. The organization and stamina required to get everyone ready, especially in the middle of winter, was often too daunting a task. Another mother, who did not drive and whose husband was away for long periods of time, described the difficulty that transportation presented when her child was hospitalized. She said, "I don't drive and am I supposed to walk from the (hospital) to NX (the name of a city subdivision) at night? The buses stop running. If I stay til he falls asleep, I end up paying a $12 taxi ride home by myself "

Although the acquisition of advocacy skills has already been discussed, several mothers stated that families of children with severe mental retardation needed to be empowered to take control of their sons' or daughter's health care. One mother stated that she and her husband were introduced to that concept at a parent support group sponsored by a local clinic and that the pediatrician had informed them of such a group. Another mother spoke of the necessity of concentrated in-home support especially in the early years and of developing a team approach with professionals from the outset. She posed this as a question stating, "Why not empower the family, why not recognize that they truly are part of the team, why not give them the skills through inservicing and collegiality and collaboration and working as a team?"

Thus, while the co-researchers agreed that many of the required services were available, it took time to find out about them, there were often waiting lists, and organizational and financial difficulties often made accessing the services impractical or burdensome. It was suggested that a supportive, coordinated system of services that empowered the family early in the child's development would eliminate many of the problems that these mothers had experienced.

Theme 7 - Co-researchers' experiences with obtaining a diagnosis for their children's condition.

As was stated previously, the diagnosis of severe mental retardation is usually not made until the infant fails to make the usual developmental progress. Although all co-researchers had received at least one diagnosis for their children's condition, the two mothers of preschool children were still exploring treatment options and were reluctant to accept a confirmed diagnosis that included severe mental retardation.

For three of these mothers, the realization that their infant was not developing normally made them seek medical advice to confirm or refute their observations. In one case the child was making the usual developmental progress until he experienced a seizure and progress stopped. For this mother, the search for a reason why this happened was of utmost importance as she stated:

> I am maybe pinning a lot of hopes on the MRI hoping that something will show up so that they can help him. It just seems so weird that he was so fine up until six months old and then it was like somebody flipped a switch and we had a different child.

All the mothers agreed that the diagnosis was shocking and devastating news and was met initially with disbelief. One mother described her reaction to the information by saying, "Initially I felt devastated, horrible grief, overwhelmed. Unable to even focus. I went through a period of months where I couldn't sleep. I couldn't do anything. I was overwhelmed."

The manner in which the mother was informed was also discussed by several mothers. Two mothers stated that the information was abruptly presented without detail and without thought to the mother's feelings and need for support. One of these mothers stated, "It was the neurologist statement, 'I don't know why mothers always think their children are going to be born healthy.' And that's all he said, after telling me he had to go through CAT scans and all this stuff. I was just shocked." Two mothers spoke of the hopelessness with which the diagnosis was presented and the emphasis on the negative aspects of the condition. One of these mothers stated:

> He told me in no uncertain terms that my son would never live outside a group home. My son would never be a father because he couldn't understand fatherhood, balance a checkbook, or never hold a job because he won't understand what's all involved. He dropped the biggest bombshell on my head that I have ever had.

Three mothers spoke of the length of time between their observation of developmental delay and the beginning of treatment. As was mentioned previously, these mothers discussed the guilt they experienced when thinking of the further damage that was caused before the diagnosis was made and treatment could begin.

As one mother stated, "I just think that we would be a lot more on the ball and E. would be a lot better off if we hadn't had to wait that amount of time."

Thus, like the mothers of children with Down syndrome, the diagnosis was a traumatic event, the effect of which was intensified if it was presented without compassion or empathy for the mother's position. However, while the mothers of older children had come to an acceptance of the extent of their sons' or daughter's disability, the mothers of preschool children were still skeptical of the diagnostic label assigned to their child. The varying nature of presenting symptoms and the gradual revelation of problematic characteristics led all the mothers in the severe group to be skeptical of initial diagnosis statements by physicians. The presenting of diagnosis information in a manner indicating that the child would not make any progress was not acceptable to these particular co-researchers either. They described a need to seek out resources that would enable them to better understand the specific nature of their child's condition. Study results suggested that only when this had been accomplished and the child advanced in age without making significant developmental gains, was acceptance of the severity of the condition possible.

Theme 8 - Societal issues regarding treatment and care of individuals with severe mental retardation.

As the co-researchers described their experiences in obtaining health care, references were made by each of them to the importance of tangible societal support of their role in the parenting of the child. As each of these mothers had at least one other child without a disabling condition, they clearly understood that the care necessitated by the child's disabilities extended beyond ordinary care. These

mothers were concerned that their children with mental retardation should have opportunities to develop to their potential. In striving to achieve this goal, these mothers described situations that indicated far from optimal conditions existed for them to achieve their aspirations for the child, however limited. For example, one mother described cutbacks in allowances for medical equpment and supplies for her son and their effect upon her ability to care for him. She said:

> I was normally allowed $1000 of medical equipment. I have a croup tent in my house, compressor, everything. Now they tell me I'm only allowed $500 in medical equipment. It's all cut back. I'm going to end up paying money and I don't have the money to pay.

Two mothers described how the behavior of certain physicians in their experience had led them to believe that some physicians were not as persistent in treating symptoms in individuals with disabilities as they were in treating similar symptoms in children not so affected. One mother said, "All along I'm really sure that if it was a kid without these disabilities, and who could talk and be like a so-called normal kid, they wouldn't have released him until they went through everything," while the other stated, "There's the pervasive thing that our kids aren't really worth it. I'm sure they would bother more with somebody who was 'with it.' Maybe."

Another mother spoke of the critical role support services played in her ability to cope with the daily management of her son. "I couldn't imagine doing it alone without any support," she said. Two mothers also spoke of the support their husbands provided by sharing responsibility for the child's care. One mother said:

> H. and I are very supportive of each other. If I'm having a bad day with E. it's okay, he can shoulder the burden and if he's having a hard time with the fact of having a handicapped child well then I'm the one that supports him so we're very fortunate.

The theme of providing life-long support services following resuscitation of infants with disabling conditions discussed by the mothers of children with Down syndrome was echoed by one mother in the present group. She stated:

> In our society we don't believe in euthanasia, we believe in the value of the human individual. This is a social choice. This is not my personal choice. This is a social reality. I am involved in this situation but by definition so is society and we need to work cooperatively as a team.

Thus the issue of societal recognition of the differing responsibilities, commitment and skills required when obtaining health care for a child with severe mental retardation was described by these mothers. Several co-researchers reported situations where they had experienced societal ambivalence towards individuals with disabling conditions. The need for societal support both in attitude and in the provision of services was critical for these mothers.

Analysis of the responses to the question, "What has been most helpful when obtaining health care for your child with severe mental retardation?"

In addition to being asked to recall their experiences in obtaining health care for their offspring with mental retardation, the co-researchers were also asked to comment on what had been most helpful to them during these experiences. Like the mothers of individuals with Down syndrome, these mothers perceived persons who put them in touch with support services as being of the most help when securing

health care for their children with a disability. For two mothers it was a knowledgable social worker who informed them of community resources and assisted them in accessing these resources, who was most helpful. This individual was also the avenue through which funding for relief services was obtained These mothers perceived the social worker as being particularly skilled in understanding maternal needs as well as those of the child and in helping the mother appreciate that the services she could access were part of society's commitment to parents such as herself. For another mother is was the pediatrician who was the community resource person, and for yet another mother it was other parents who performed this function. Regardless of who was the informing individual, it was the tangible support offered by individuals that these mothers described as being most helpful to them. The nature of this support was described by one mother in the following way:

> I have had a marvelous social worker who has pointed out to me things I didn't know existed, who has "upped the ante" on my requests at times because he thought they were too modest and didn't meet my needs, and who has forced me to look at certain issues under the issues, that is to get at the real needs, not just the apparent needs, to get at my needs, not just what I perceived B's to be.

The availability of community supports that were easily accessible was highly valued by these mothers. While these resources existed, it was an informing individual who knew of them and who made the mother aware of her need that made these resources accessible to her.

In summary, the data analysis illuminated eight themes that were held in common by the co-researchers in the group with children affected by severe mental retardation. They revealed their children's condition was not evident at birth but was determined gradually. This impacted upon diagnosis and treatment as there was usually considerable time between when the mother first suspected something was wrong with the infant and treatment for the condition began. These mothers agreed that being presented with a diagnosis of severe mental retardation was shocking and unacceptable news initially, but for the mothers of older individuals, acceptance has come gradually. The mothers also described their sons and daughter as having feeding difficulties as well as several other health related problems that could include seizure activity, a reduced ability to communicate, deficient or complete absence of mobility, a hearing impairment, or a severe behavior disorder. Because of these associated difficulties, the child required constant supervision and was dependent upon others for his or her personal care needs. The mothers described themselves as individuals who networked with other mothers in similar circumstances, who were assertive, and who advocated strongly for their children's health care needs. These mothers agreed that they had experienced anger and frustration over waiting lists for services, the diagnosis and the manner in which it was presented, service inequity and physician or nurse behavior, especially in hospital situations. These mothers also experienced guilt over disability and treatment issues and worried about their children's future. Helpful physicians were described as caring individuals who were concerned about the child, the mother and the family and who included the mother as part of the care-giving team. These physicians were knowledgable of community resources, were thorough in their

diagnosis and gave the parents hope for their child's progress. All mothers discussed how health care services were provided, indicating that services were fragmented, took time and effort to access, resulting in added stress to the mother. When the children were hospitalized, the mothers agreed that staffing was not adequate to monitor the health problems, especially the seizure activity experienced by the children, resulting in the mother providing much of the care. These mothers agreed that they needed societal recognition of their offspring's inherent worth and the necessity of extra support services to parent the child adequately. Individuals who helped them to delineate their need for services and who informed them about such services were perceived as being most helpful to these mothers when they obtained health care for their children with mental retardation.

Between-group Analysis - Themes Held in Common by All the Co-researchers

Theme 1 - Child characteristics.

All of the mothers stated that the children with mental retardation had multiple health problems, however the health problems exhibited by the child with Down syndrome, once the birth anomalies were corrected, were not as severe or life threatening as those of the children in the group that was severely affected. For example, none of the individuals with Down syndrome experienced seizure activity, a condition that had caused life threatening situations for individuals in the severe group. One mother spoke of seizures her daughter experienced during which the adolescent stopped breathing. Another mother spoke of the side effects of an anticonvulsant drug which in the short term resulted in severe nocturnal bleeding and in the long term caused irreparable damage to the liver. Although the mothers of the individuals affected by Down syndrome stated that their son or daughter had

more health related problems and recovered more slowly from common illnesses than their nondisabled siblings, the health related problems described by these mothers lacked the urgency and intensity witnessed in the interviews with mothers of severely affected individuals. The children with Down syndrome were also more independent and required less intervention in personal care than did the individuals in the severe group. Because these children could walk and were generally able to communicate their basic needs to hospital staff, hospital stays did not necessitate the presence of the mother at all times as was the case among the mothers in the severe group.

Theme 2 - Co-researcher characteristics.

All mothers shared a number of common characteristics. They all stated that they had become assertive individuals as a result of their overall experiences with their son or daughter with a disability and had acquired advocacy skills that enabled them to get the services they deemed necessary. These skills were acquired over time and were used not only to obtain the health care services that were required but were used throughout the spectrum of service provision. These mothers expressed a fierce loyalty to their children and were determined to obtain the services their son or daughter required, as long as they possessed the energy and stamina required. One mother in each group spoke of instinctual behavior that she related to motherhood and which emerged at critical times in her experiences. This was described in the following manner by one mother:

> It was just the old, what is the instinct, the mothering instinct or whatever came out and I thought how can you say this about my son and I don't

believe you and it's our responsibility to bring E. as far as he can, not just try to keep him where he's at and accept that.

Most of the mothers had changed doctors when necessary in order to find someone with whom they could relate. In addition, most of the mothers stated that they were knowledgable of their children's health status and took control over the treatment of a condition when they were in disagreement with physician opinions or could not get the services or treatment they thought was necessary.

Theme 3 - Co-researchers' feelings regarding their experiences in obtaining health care for their children with mental retardation.

Most of the mothers expressed feelings of anger and frustration at some point while obtaining health care for their children. For the mothers of individuals with Down syndrome it was anger expressed at the birth of the child and over attitudes of disrespect expressed by physicians and nurses. While the mothers of individuals with severe mental retardation experienced anger, these feelings emanated from a variety of sources including the waiting time for tests and services that would assist in the diagnosis as well as attitudes indicating a lack of valuing of individuals with mental retardation.

All mothers except one expressed feelings of frustration over the difficulty or delay in obtaining services for their children. For the mothers in the Down syndrome group, difficulty in obtaining speech therapy was a dominant theme while the mothers in the severe group expressed frustration over the waiting lists for specific diagnostic tests and subsequent diagnosis, and for services such as equipment acquisition.

Theme 4 - Physician characteristics that have helped the co-researchers in obtaining health care for their children with mental retardation.

All mothers held a number of helpful physician characteristics in common. They all agreed that such a physician was a caring individual who included the mother as part of the care-giving team and helped her in achieving the health care goals she set for her son or daughter. Caring was defined somewhat differently by each of the two groups of mothers. Mothers of children with Down syndrome defined caring as being able to relate well to both the mother and the child, that likely reflected an attitude of valuing both the individual with mental retardation and the individual who was the primary care giver. An atmosphere of mutual trust was set by this physician at appointments. The mothers of children with severe mental retardation defined caring as an expressed concern on the part of the physician for the health and well being of both the mother and the child. This involved an acknowledgement of the extra care-giving demands that parenting such an individual made on the mother and a realization that the child's health status was, to a degree, dependent upon the status of the mother's health. While this was expressed by all the mothers in the severe group only one mother of a child with Down syndrome specifically mentioned this factor in providing health care for her son.

Theme 5 - Co-researchers' experiences with obtaining a diagnosis for their children's condition.

All birth mothers stated that the diagnosis of mental retardation was a traumatic time for them. The content analysis revealed that the emotional trauma experienced by the mothers of children with Down syndrome at the time of

diagnosis was eased by physicians who were aware of the significance of the diagnosis for the mothers and expressed empathy and compassion. The trauma was lessened as well if the nursing staff was available to provide sympathetic care to the mother and practical advice for the care of the infant. Unfortunately, the mothers in the severe group all indicated that the informing physician was abrupt in the manner in which the diagnosis was presented and painted a hopeless future for the child, suggesting to the mother that there was little chance for developmental progress. Several mothers in this group spoke of experiencing feelings of abandonment until they encountered social workers or a pediatrician who informed them of support services that were available to them, including parent support groups and relief services. These mothers spoke of the empowering consequences that such services provided for them, following the feeling of powerlessness they initially experienced at the time of diagnosis.

Theme 6 - How services have been delivered has influenced the co-researchers' experiences in obtaining health care for their children with mental retardation.

While all the interview material contained statements referring to how services were delivered to these mothers, there were no themes shared in common by all the co-researchers. While the mothers of individuals with Down syndrome spoke of the necessity for the coordination of services between the primary care physician and the mother, the mothers in the severe group made few comments regarding their access to health care services except those specific to hospital care. Here these mothers were unanimous in their statements concerning the inability of hospital staff to care for their child that necesitated their remaining in hospital for the

duration of the stay. One co-researcher of a child with Down syndrome stated that she also remained in hospital when her son was a patient. The other three mothers of individuals with Down syndrome had less to say about hospital care after the birth of the child.

Theme - 7 - Societal issues concerning the treatment and care of individuals with mental retardation.

While there were no themes held in common by all the co-researchers in the study regarding societal and moral issues of treatment and care, a number of issues were raised by the majority of co-researchers. For example, all of the mothers spoke of the necessity for support services, some of which related to the health of the child such as the provision of funds for medical equipment. A majority of mothers also had encountered physicians whose attitude towards their child led the mother to believe that the child would not receive the same quality of care unless the mother intervened, because the child was perceived as being somehow less than his or her nondisabled peers. Half of the mothers stated, that since present societal mores dictated the resuscitation and treatment of neonates with congenital conditions or brain damage as a result of birth trauma, it followed that the necessary services required throughout their lifetime needed to be established as well. These mothers pointed out that presently the services necessary to adequately sustain the individual and his or her family through the life span were fragmented, difficult to access and, in some cases, inadequate. They stressed that 'cradle to grave' services were required if parents were to cope with the added stress of parenting a child with mental retardation.

The co-researchers in this study shared a number of common experiences when obtaining health care for their children with mental retardation. These described the global issues of treatment equity and valuing individuals with reduced intellectual capacity. Others were concerned with the capability of the present service delivery system to meet the unique health care needs of children with mental retardation. This next section will discuss these issues in the light of other research, including the preliminary study (Wilgosh & Chomicki, 1991).

Chapter V

Discussion and Conclusions

This chapter will serve several purposes. First, this chapter will briefly compare the results of the preliminary study cited above with the results of the present study. The topics of health care service provision and societal issues regarding the care and treatment of individuals with mental retardation, raised by the co-researchers in the present study, will also be explored by comparing study results with research from the literature review. This chapter will also discuss factors that limit the results of the study. Finally, conclusions and implications of the study will be stated.

A Comparison of the Results of the Preliminary Study with the Present Study

The preliminary study was designed to compare and contrast health care concerns between parents of children with moderate mental retardation and parents having children in the severe range of retardation. Respondents were specifically queried as to their concerns regarding the provision of health care to their children with mental retardation. In that study, statistically significant differences between the two groups of respondents were found on two aspects of health care provision. Respondents in the moderate group expressed fewer overall concerns with health care provision than did their counterparts in the severe group. They also expressed fewer concerns on the hospitalization variable than did the respondents in the severe group. While the present study did not specifically ask the co-researchers about their concerns when obtaining health care for their children with mental retardation, a number of concerns were expressed. However, unlike the preliminary study results that found a difference between the two groups of respondents in the total

number of concerns expressed, the majority of the concerns arising out of the present study, were held in common by all the co-researchers. This was likely due to the format of the investigation that differed considerably between the two studies. The questionnaire design of the preliminary study used a forced choice format that specifically asked respondents about their concerns when obtaining health care. It is possible that when conducting a brief survey of experiences, surface differences due to level of retardation emerged. The present study allowed the co-researchers to provide expansive descriptions of a wide range of health care experiences, not just brief descriptions of their concerns. What emerged from these interviews were themes that were common to the experience of mental retardation. Given the opportunity to describe and reflect, level of retardation was a less significant factor for the respondents, than was the presence of retardation, per se.

Present study results did agree with preliminary study results on one health care theme, where differences between the two groups of mothers were found. When describing the hospitalization of the children with mental retardation, the co-researchers in the severe group had more concerns than their counterparts in the Down syndrome group, a finding reported in the preliminary study results.

In the present study, the co-researchers in the severe group realized that hospital staff could not meet the multiple and often subtle needs of their children who were disabled. The mothers of individuals with Down syndrome did not express this same level of concern with hospital care. It is likely that children with Down syndrome could communicate their needs to hospital personnel and the constant attendance by the mother was not critical to adequate hospital care provision. In addition, the children with Down syndrome experienced fewer

hospitalizations than did their more severely affected counterparts, and the co-researchers had few recollections of hospital experiences other than at the time of the birth of the child. On the other hand, for these mothers (i.e., those having offspring with Down syndrome), attendance at appointments with physicians was a primary concern. This was considered a lifelong necessity because of the subtle manifestation of certain conditions in individuals with Down syndrome, and the inability of these individuals to express these subtle changes. This was also due to some physicians attributing presenting symptoms to mental retardation. Consequently the presenting symptoms were ignored by the physician. This behavior has been documented in the literature as "diagnostic overshadowing" (Beange & Bauman, 1990; Reiss, Levitan, & Szysko, 1982). What is interesting from the results of this study was that several of the co-reseachers instinctively recognized the phenomenon and responded appropriately to it.

In the light of these two investigations, it would appear that the mothers of individuals with severe mental retardation needed to exercise more vigilance over all aspects of their sons' or daughter's health than did the mothers of the children with Down syndrome. This was likely due to the direct relationship between level of dependency and maternal involvement with care. This study revealed that individuals with severe retardation were more dependent upon others for all aspects of daily living than were individuals with Down syndrome. There was a concomitant difference in maternal involvement as a result of this difference in level of dependency.

The Effect of Frequent Exposure to Health Care Services on Parental Perceptions of Service Delivery

As was previously stated, it would appear that, given an opportunity to verbally express their experiences, the mothers of individuals with Down syndrome had similar concerns to mothers of children who were more severely affected. Because both groups of children required frequent consultations with physicians, it was possible that their mothers also developed more apprehensions as a result of this increased contact. This finding would appear to be supported by research on chronic conditions that included mental retardation. In those investigations, frequent exposure to the health care system resulted in reduced trust and increased friction between professionals and parents especially when professionals failed to recognize parental expertise (Gill, 1987a; Gill, 1987b; Thomas, 1986). From this perspective then, the co-researchers in this study shared common experiences with parents of children not affected by mental retardation. What was unique to the mothers interviewed for this study was the *effect* of mental retardation on service provision. This phenomenon resulted in service delivery gaps that were keenly felt by the co-researchers and led the co-researchers to comment on global concerns that focused on public perceptions of mental retardation.

Global Concerns Regarding Health Care Provision and Societal Reponses to the Care and Treatment of Individuals with Mental Retardation

All co-researchers related at least one experience where they felt their sons or daughter had been inequitably treated by physicians because of the presence of mental retardation. While the majority of these women changed physicians when

that happened, there were some instances, for example, when seeking the advice of specialists and subspecialists, where finding another doctor was impractical or impossible. It was these circumstances that most often proved the most difficult for these mothers to understand and which separated this group of individuals from mothers of children with chronic conditions other than mental retardation.

The presence of negative attitudes towards individuals with disabilities exists in the general population (Livneh, 1982). The literature review supported these mothers' accounts of pessimistic or negative attitudes towards individuals with mental disabilities by some health care professionals (Altman, 1982; Cormier, 1982; Kelly & Menolascino, 1975; Kugel, 1986; Patterson, 1983; Ryan, 1983; Wolraich & Siperstein, 1983) and differental treatment due to the presence of mental retardation (Aranosian, 1983; Todres, Krane, Howell, & Shannon, 1977). It was likely that many physicians, especially those with no, or limited, exposure to individuals with disabling conditions, simply reflected the attitude still prevalent in society (Wolraich, 1982). While a number of researchers have reported on attitude change as a result of training, others described physician training to be particularly sparse in the area of mental retardation and developmental disabilities (Howells, 1991; Lesser, 1986; Powers & Healy, 1982; Willer, Ross,& Intagliata, 1980) due, largely, to the past institutionalization of such individuals and to the competition in medical school curricula for subject matter inclusion (Bradley, 1988; Guralnick, Richardson, & Heiser, 1982). It was likely that many physicians have had little training in the care and treatment of individuals with mental handicaps and expressed the same fears regarding handicapping conditions that are still generally present in society (Lesser, 1986). Indeed, study results supported that finding with

several co-researchers in each group expressing an understanding of the inexperienced physician perspective.

In another study, other parents of children with mental disabilities noted that physicians have not been helpful in providing information regarding specific problems and have not been knowledgable about community resources (Glenn, 1987). Considering the rapid growth of community integration for individuals with intellectual impairments, it is not surprising to find gaps in the delivery of generic health care services to individuals who, until very recently, were residents of large, self-contained institutions. Consequently, there is a growing need to include training on the specific health care needs of individuals with mental retardation on the curricula of health care professional training institutions and to provide inservice training to practicing professionals (Beange & Bauman, 1990; Wilson & Haire, 1990; Wolraich, Siperstein, & Reed, 1991). Thus a gap currently exists between the availability of easily accessible services and knowledgable service providers, and the expectations and needs of service users. The anger and frustration expressed by the co-researchers in this study would appear to reflect this gap. Featherstone (1980) noted that physicians were the group most targeted for the expression of parental anger. In the light of the considerations, stated above, it is understandable that the mothers of children with mental retardation were disconcerted about the expectations placed on them to keep these individuals at home and the lack of facilities and personnel to assist them in carrying out those expectations.

A comparable study in disparity was the contrast in experiences described by the mothers of children affected by Down syndrome at the time of diagnosis.

Two of the co-researchers described supported situations both for themselves and their infants at the birth. They reported that the informing physician(s) were knowledgable about the syndrome and gave the mothers accurate information as to the potential of individuals with Down syndrome as well as information regarding community supports. Both mothers described the nursing care as being informed, empathetic and helpful. Both mothers were referred to early intervention programs which began several months after the child arrived home following treatment for heart and digestive difficulties. The experience of the third mother was completely different. This mother was not given accurate information, was not allowed to hold the child following the birth and was encouraged to place the infant into foster care. Several articles have reported on the critical role of the informing physician (Cooley & Graham, 1991; Murdoch, 1991) and of the improved outlook for infants with Down syndrome (Cooley & Graham, 1991; Michaels, 1990; Msall, DiGaudio, & Malone, 1991). With increased knowledge as to the specific health care needs of individuals with Down syndrome, and with greater community inclusion of these individuals, it is likely that experiences of pessimism and hopelessness will be repeated with less frequency in the future. Similarly, increased training in mental retardation to health care personnel, and knowledge of the needs of parents at the time that they are informed of their child's disability, are likely to result in fewer informing situations such as were described by the co-researchers in the severe group (Cooper, 1991; Cottrell & Summers, 1990). Finally, with the passage in the United States of P. L. 99-457, requiring mandatory early intervention and educational services to all children with handicaps from birth to five years of age, we are likely to see a heightened awareness and growing body of knowledge on the

needs of young children with mental retardation on the part of health care professionals (Humphry & Link, 1990; Mahoney & O'Sullivan, 1990). This, in turn, is likely to result in a decreased pessimism on the part of physicians and other health care professionals on the prognosis of all individuals with mental retardation.

All of the co-researchers expressed the need for a variety of community supports in parenting the child with mental retardation. Whether provided by the primary care physician, the social worker, another mother, or a combination of these individuals, the support of another knowledgable individual was considered essential by all the interviewees, especially when they felt most vulnerable, such as at the time of diagnosis or in a crisis health care event. Support was expressed in very tangible ways including the need for: accurate information especially at the time of diagnosis, emotional support that gave the parents hope for their child's progress, early intervention services that informed parents about habilitation and coping strategies, and relief services that eased the stress of constant care requirements. Furthermore, these co-researchers were very vocal in expressing the ambivalence they perceived in the provision of health care to individuals with mental retardation. They described a gap between societal philosophy and practice that went to heroic lengths to resuscitate infants but did not provide lifelong follow-up services.

In summary, the co-researchers in the present study concurred with the preliminary study respondents in their experiences regarding the diagnosis and hospitalization of their children with mental retardation. Co-researcher perceptions of service inequity and devaluing of individuals with mental retardation by certain physicians were supported by evidence from the literature review. However these

and the other results reported in the present study must be considered in the light of certain limitations.

Limitations of the study

There are several factors surrounding the sample used for the study and the methodology that limit the conclusions that can be drawn from this investigation.

Limitations Regarding the Sample

The women who participated in this study were volunteers, not randomly selected from a list of all possible participants. In addition, they had all answered a questionnaire that asked specific questions about the topic. These realities could have introduced some bias into the results. For example, those participants who had school-age children affected by mental retardation, all belonged to a parent support group. It is possible that those who volunteered were particularly vocal individuals whose experiences were not representative of the population. Similarly, it was possible that participation in the survey study would affect what was said, or emphasized, in the interview. In responding to the questionnaire, the participants had already reflected on the topic and so a pure expression of their experiences might not have been possible. Valle and King (1978) stated that the verbal expression of the co-researcher's life-world or experience represented a reflective state rather than one of pre-reflection. It is possible that the interview data could have been subtly altered by the co-researchers' having already reviewed their experiences in responding to the quesionnaire.

Comparisons made with the preliminary study, especially those involving differences between the two groups of co-researchers need to be interpreted cautiously. In the preliminary study, moderate mental retardation was defined in

adaptive behavior terms. This likely resulted in some respondents having children moderately affected by retardation but possessing characteristics other than those of Down syndrome. In this study, all participants in the moderate group had offspring affected by Down syndrome who had a relatively high number of health concerns, especially in infancy and early childhood. One of these individuals also had a severe visual impairment in addition to the presence of Down syndrome. In addition individuals with Down syndrome also have similar health problems resulting from the syndrome. It is possible that a more representative sample might have experienced fewer health problems, altering the between-group results of this study. In the light of those circumstances, more differences between the groups might have resulted.

Overall, respondents in the moderate group were better educated and more articulate than respondents in the severe group. It is possible that these characteristics influenced their experiences in obtaining health care (e.g., how they interacted with professionals, how persistent they were in obtaining care), how they perceived those experiences and their verbalization of those experiences. Thus, their descriptions were likely more detailed and elaborate than those of their counterparts in the severe group, resulting in a qualitative difference in the content of the interviews.

The sample size was small and drawn from white, middle class neighbourhoods in a western Canadian city, where certain social support agencies were available and a socialized health care scheme was in place. Extrapolation to other cultural groups and environments with a different social support sytem and service delivery system, might not be appropriate.

Limitations regarding the interview protocol analysis

The researcher's skill in the analysis of a phenomenon will be reflected in the quality of the results obtained. An essential ingredient of phenomenological methodology is the creative leap made from what is said to what is meant (Colaizzi, 1978), or, as described by Berg (1989), the move from manifest content to latent content. Much of the protocol analysis revealed expressions of a concrete nature, concerned with specific aspects of the experience. It is possible that these results were due to the nature of the topic under consideration . It is also possible that a more experienced researcher would have brought more insight to the analysis process that would have enriched the "meaning" portion of the analysis.

While the results of the study must be understood in the light of these limitations, there are a number of implications, both for parents and health care professionals, that can be considered as a result of this study.

Implications for Parents and Health Care Professionals

Study results indicate that the mother, as the primary care-provider, is likely the critical figure in obtaining health care for her child with mental retardation. In order to secure the most comprehensive and effective health care services, mothers of these children require knowledge of both their child's condition and how to access the health care system. The mothers in the study indicated that they had had little experience with the provision of health care services prior to the birth of the child with the disability. Networking with others in similar circumstances is a very effective way for mothers to inform themselves as to which individuals and services might best help her to achieve her health care goals for the child. Using the experience of others, she can more directly access services and avoid the trial and

error difficulties that often accompany problem solving in unfamiliar situations. Successful accomplishment of one's goals through collaboration with skilled individuals results in a sense of control and empowerment in meeting the health care needs of the child.

Other individuals such as social workers and informed physicians are also key players in accessing health care services. These persons act as valuable partners, providing both moral support and knowledge of practical services that increase the extent and effectiveness of health care services. Looking carefully to find individuals who understand the mother's perspective and who will support her in her concerns for her child's welfare is appropriate behavior in these circumstances. Study results suggest that establishing a collaborative relationship with an interested and informed primary care physician is a necessary element in securing health care that is satisfactory from the mother's perspective. Important to that relationship is that individual's ability to coordinate services and to act as a liaison and support between specialists and the parent.

Study results would also suggest that the expectations held of subspecialists on the part of the mother should likely vary from those required of the primary care physician. While a caring and familial attitude is required of the primary care physician, subspecialists are likely to be less familiar with particular conditions and more concerned with applying their expertise to the particular problem experienced by the child. Parental understanding of the different roles played by health care professionals is important in the setting of realistic expectations and subsequent achievement of maternal and broader parental goals.

Successful parenting of a child with mental retardation requires particular skills and knowledge. The extra demands required of parents often lead to feelings of anger, frustration, hurt and guilt. Such feelings often accompany parents to appointments with physicians and during hospital stays. Awareness of one's mental and psychological state, accompanied by an open, honest attitude with expectations clearly stated, is an important attribute that is likely to increase the likehood of understanding of treatment goals between parents and health care professionals.

Pediatricians or family physicians are likely to provide primary care to individuals with mental retardation. Awareness of family functioning and the particular role played by the mother in providing health care for her child with a disability are essential ingredients in the provision of care to these families. Study results suggest that physicians providing primary care have a familiarity with mental retardation and are aware of current treatments as well as community resources that assist the family in coping with the particular demands presented by the condition. An understanding that many mothers are well informed as to their child's condition, are assertive and advocate strongly in order to achieve their goals, is also important.

Study results indicate that the time of informing or diagnosis is a very traumatic event for families of individuals with mental retardation. It is a time when they require extra support and encouragement. Acceptance of a disability takes time, especially when the extent of the impairment is revealed over time. Parents need to know that everything possible is being done to diagnose and treat their child's condition and that their child will make some developmental progress, regardless of the severity of the condition. Communicating diagnostic information

should involve a keen awareness of the impact on parents of such information. Compassion and understanding of the parental perspective is important at this time. A team approach that includes physicians, nurses, social workers and other parents who are available to answer parental inquiries, to give practical advice and to put parents in contact with early intervention services is essential. This approach would facilitate the beginning of the coordination of services and a collaborative relationship with a primary care physician. Thus supported, the family is assisted in developing successful coping strategies and is not likely to experience the feelings of abandonment described by a number of the mothers in this study.

Mothers of children with mental retardation are more likely to set realistic goals for the provision of health care if they know that their child is accepted and valued by those providing treatment and care. Study results suggest that the establishment of a relationship that fosters and encourages parental participation in decision making is desirable. Allowing the mother to talk openly about her concerns, as well as admitting one's own limitations and willingness to refer to others if necessary, are important physician behaviors that foster this relationship.

Most of the co-researchers spoke of the importantce of a universal health care system. Release from the financial burden of health care expenses is important to the reduction of stress among families of children with disabilies. Similarly, when the child with severe disabilities is hospitalized it is important that the mother is supported in her role of providing a large share of the care in hospital. Ensuring that care for siblings and transportation for the mother is provided, faciltates this role and is required in certain families with limited resources.

In summary, mutual awareness of the particular role played by physicians and parents in providing health care maximizes the potential for the provision of the best possible care for the child. Such understanding assists the family in coping with the extra care demands required by the presence of a child with a disability and fosters feelings of satisfaction on the part of both parties.

Conclusion

The presence of multiple problems in individuals with mental handicapping conditions requires a variety of physician specialists and a well coordinated system of service delivery. In addition, the life threatening nature of some conditions necessitates efficient and quick access to emergency treatment where staff are knowledgable and well trained. Similarly, in-patient hospital care for individuals with mental handicapping conditions requires additional expertise than what is required for nondisabled populations. These mothers' experiences have pointed to the lack of professional training and expertise in mental handicapping conditions and family support. The need for improved training in mental retardation on the part of physician educators has been documented in the literature in terms of providing necessary care (MacFaul, 1986), but also in the area of preventive medicine (Szymanski, 1987). A number of studies have also shown that training to improve practicing physicians' knowledge and use of community resources can be successfully accomplished (Powers & Healy, 1982; Singh & Winton, 1984). What is also apparent from these interviews is the need for a transdisciplinary, collaborative approach to the care of individuals with mental disabilities. Crocker, Yankauer, and their colleagues (1987) have discussed the need for a network of health care professionals, in addition to a primary health care provider who provides

continuous and long term care for individuals with mental retardation. This network would provide advice, specialist care and information on services that could be accessed by individuals involved in the care of persons with mental retardation. Similarly, Jones and Birney (1986) described the development of a community mental handicap team model that included a training and service component with specialist clinics in various community centres.

A new decade of service delivery to individuals with mental retardation is just beginning. Some of the latest research articles, especially those concerning physician knowledge of mental retardation and the services available, are encouraging. Articles such as those by Cooley and Graham (1991) and Msall et al.(1991) indicated a high level of physician awareness of the specific health problems, the learning potential and the services available for individuals with Down syndrome. They also presented enlightened accounts of the parental perspective and the need for a collaborative approach to the care of these individuals. Some of the issues regarding the diagnosis of individuals with mental retardation raised by the co-researchers in this study, were directly addressed by these researchers. It is possible that such insight and knowledge will also be extended to those whose patient list includes children affected by severe mental retardation.

Louis Rowitz (1989), in an insightful editorial on trends in mental retardation in the last decade of this century, suggested an expansion of the health care delivery system to this population that included a retraining of health care providers to the specific health care needs of these individuals through the life span. This eventuality combined with increased research on family functioning and

disability, would be instrumental in alleviating some of the problems outlined in this study.

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Appendix A

The following table represents a summary of the results of the preliminary study in which (M) indicates responses of individuals in the moderate group and (S) indicates responses of individuals in the severe group.

Table A-1

Percent Agreement with Questionnaire Statements - Severity of Retardation Group

The parent-professional relationship

70% (M) 48% (S). Most physicians who I have encountered display a positive attitude toward my son/daughter

56% (M) 56% (S). Most physician's are supportive and understanding of the impact my son/daughter's condition has on me and the rest of my family.

89% (M) 64% (S). Generally, experience with my son/daughter's physician(s) has been a positive one.

74% (M) 56% (S). Generally, I find nurses to be empathetic and understanding when working with my son/daughter.

70% (M) 68% (S). Physicians willingly include me as part of the decision making team when it comes to my son/daughter's health care.

41% (M) 28% (S). When I was told my son/daughter was disabled, efforts were taken by the physician to be understanding, supportive and considerate of my feelings and emotions.

Parental Perceptions of Professional Competency

41% (M) 24% (S). Most health care personnel have adequate knowledge regarding my son/daughter's condition.

56% (M) 20% (S). Getting a diagnosis for my son/daughter's condition was not difficult.

(table continues)

0% (M) 4% (S). I do not think that nursing and physician specializations in mentally handicapping conditions is important.

4% (M) 4% (S). Staff inservice training in mental retardation to health care personnel is not very important.

Service Delivery

48% (M) 24% (S). I do not have to go to many different places to get all the health care needs of my son/daughter met.

52% (M) 44% (S). Government funding is adequate to provide quality health care for my son/daughter.

22% (M) 24% (S). Information about health services for disabled children and adolescents is readily available to parents.

0% (M) 8% (S). Rehabilitation practitioners (individuals specially trained in the care and treatment of disabled individuals) would not be useful on pediatric wards.

Hospitalization

15% (M) 4% (S). When my son/daughter is hospitalized, I know that careproviders will be able to understand his/her method of communicating.

52% (M) 24% (S). When my son/daughter is hospitalized, I worry whether careproviders will know how to feed him/her.

26% (M) 12% (S). When my son/daughter is hospitalized, I know that the staff will treat my child in the same way that they treat nondisabled individuals.

33% (M) 8% (S). When my son/daughter is hospitalized, he/she will be included in the same activities as other individuals.

11% (M) 16% (S). When my son/daughter is hospitalized, I know that my child's toileting schedule will be maintained.

(table continues)

7% (M) 0% (S). When I am at the hospital with my child, I do not provide much of my son/daughter's care.

67% (M) 72% (S). When my son/daughter is hospitalized, I am usually calm and able to work effectively with nurses and physicians.

19% (M) 24% (S). Hospital admissions are not traumatic for my son/daughter.

Appendix B

The following two tables include the tabular presentation of one interview protocol and illustrate the two levels of content analysis described in the text (page 39). While much of the interview protocol has been included, the tables present only the meaning units of the interview, not the complete contents . The tabular representation of this particular co-researchers's interview was chosen because it was representative of the themes and thematic clusters, and was relatively brief.

Table B-1

Thematic Abstraction of Ns Experiences in Obtaining Health Care for her Daughter

	Two Levels of Abstraction	
Excerpts from Transcribed Intervier	Paraphrases	Themes
1. We started out with very good doctors that cared, that seemed to be not only caring for her but also for us. He's always very caring.	Mother values compassion and wholistic view of the need to maintain family health	Physician characteristic - caring for child and family Mother characteristic - needs to be cared for too.
1a. She's become very, very strong and she really doesn't have the problems anymore.	The child is healthy now	Child characteristic - healthy
2. As far as dental, we had to do a lot of searching first of all. Go to a number of dentists before we found one who could cope with her and take things in stride	Mother had to shop around to find a dentist who understood child's behavior, was relaxed with child and could get child to cooperate	Need to shop around for health care providers who can work with child.
3. Finally someone suggested to us going to Dr. C.	Mother acted on referral suggestion	Word of mouth referrals can be successful
4. It seems that we've gotten in with a whole team that sort of work together at the hospital and they are very caring and very understanding and we've had wonderful success.	Health care providers work together as a team, know and care about the child and her family.	Health services are coordinated in one hospital. Health care provider characteristis - caring and understanding.

(table continues)

Excerpts from Transcribed Interview	Paraphrases	Themes
5. And he tried the first time to do it in his office and it just didn't hold so we had to hospitalize her and he did it there.	Usual procedures did not work with this child	Health care providers sometimes need to adapt techniques to unique needs of these children.
6. We've always had to hold her down, several of us hold her down for the first years, but the last time my husband took her, he said she was very good. She's becoming more trusting	Repeated successful experiences and child maturation have reduced fear and care providers can use less intrusive behavior when treating child.	More cooperative behavior with care providers is seen now that child is an adolescent.
7. I think through all the bit with, even before the heart surgery, what do you call the procedure where they put the tubes in the arteries? Anyway from small on she's always had this fear of what they are going to do to her and I think with the heart surgery, of course, a lot of traumatic experiences occurred at that time too.	Procedures required to correct heart difficulties associated with Down syndrome left the child traumatized and fearful of hospital situations	Child fearful of hospital situations
8. But all of these things, as young as she was, she had a good memory. She remembered a lot of things and so when we put her back in, took her in the following year for a tonsillectomy, what a struggle we had to get her to the operating room....Well, at four years of age...she knew what was coming but she wouldn't stay on the stretcher. She wouldn't stay anyplace. She even heaved one of these huge linen carriers piled with linen.	Child is extremely fearful of unknown hospital situations because of past experiences and displayed uncontrollable behavior when faced with a similar situation.	Child fearful of hospital situations

(table continues)

Excerpts from Transcribed Interview	Paraphrases	Themes
9. He said you can phone us any hour of the day or night if there's anything.....I may be on that phone at 6 or 7 in the morning to his house and there was never a thing about being gotten out of bed.....and then he would prescribe and he would tell us what to do, you know, what to do in between and then we would go in when it was conveneint. so I really felt that over those first years, that was very important.	When the child was small and had more medical needs, mother felt comfortable phoning the physician when she felt she needed his assistance regardless of the time	Physician availability important
10. Dr. T. said a lot of doctors would just shut off and not do anything. They feel, "Oh well, so what if they're (child with Down syndrome) fatigued or so on, there's no problem, just let them go." He says, "I don't believe in that. I believe in giving them the best possible chance there is."	Doctor is supportive of the mother's concerns and is willing to use all resources despite presence of Down syndrome	Physician supportive of parental concerns. Mental retardation does not affect treatment.
11. They (the doctors) feel we're caring parents and we deserve to get the very best for her because we'll put out everything. We're there.	Mother sees care provision as a cooperative effort	Quality health care provision requires physician/parent cooperation
12. There was no differentiation between having a handicapped child and having a regular child. They would do this kind of thing, I felt, for any kind of person. because they were mentally handicapped they were not less, they weren't perceived as being less important, that they deserved every possible treatment or care that was needed.	Mother perceived physicians would provide the same care for any child whether retardation was present or not	Mental retardation does not affect treatment

(table continues)

Excerpts from Transcribed Interview	Parphrases	Themes
13. He says, I think you can take better care of her at home, then having her lying in the hospital here. You just call me if there's anything that comes out of it."	Physician encouraged mother to care for child at home but projected availability if necessary	Physician expresses confidence in mother's caring abilitiy.
14. The gynecologist and the pediatrician both were very caring and put us in touch with a family who was closely linked with the new Mayfield program....They wanted us to get all the help we could there.	Physicians were knowledgable of community resources and made them available to parents at birth of child	Physicians are aware of needs of family and knowledgable of community resources
15. We found the nurses at the hospital, the head nurse in the pediatrics very good. They took a lot of time to come and talk and help. She (the infant with Down syndrome) was able to nurse which is not that common with Down syndrome. They usually don't have enough strength but they encouraged me on.	Nursing staff offered psychological support and practical advice right after the birth.	Supportive attitude at birth on part of hospital staff towards child with disabiling condition.
16. But they were very good, very caring at the hospital and they tried to give us as much help as possible. Where to go or what to expect and they also wanted that support in the community.	Hospital staff cared that family was prepared to care for the child at home	Hospital staff caring

(table continues)

Excerpts from the transcribed interview	Paraphrases	Themes
17. I didn't feel we got the support from the health unit, the understanding and support from the health unit that we should have l They were not all that encouraging or supportive....Comments like, "Oh well, she'll never go very far," or "What do you expect, after all, she's Down syndrome."Things like that were not encouraging. Normally from all the other areas we've had very encouraging kind of remarks	Follow-up from the health unit was not supportive Staff were not encouraging in their comments which varied with feedback from what parents had experienced at other community resources	Health unit not supportive
18. I found at the health unit, It wasn't the same kind of, I don't know probably an uninformed or uncaring few nurses. Could be that. I don't know. I'm not sure but I just feel that they were not in tune with what was heppening and not in tune with the line of people we had been working with.	Health unit perspective differed from that found elsewhere. and did not seem to be current	Health unit staff not supportive or encouraging.
19. When Dr. M. was away one day and we had taken her in for an appointment. She was crying her heart out and the other doctor with him.....finally took her ahead of some of the others and he just yelled at me when he got in the office. He said, "Why in the hell did you have her to start with?" Oh he was absolutely nasty.	Not all physicians expressed support and encouragement	Differing attitudes toward mental retardation exist among physicians.

(table continues)

Excerpts from the transcribed interview	Paraphrases	Themes
20. His attitude was exactly the opposite to what we had experienced and I mean I think he would have been the same probably with any other child with special needs and his treatment of course was immediately,"well you shouldn't have had children like that, now that you have them give them drugs right away to subdue them or to keep them under control." And that just seemed to be his attitude. He didn't have the time of day really to come to grips with understanding them or us.	Mother experienced divergent physician behavior. Felt that he was not interested in the child, not supportive of her caring role Consequently, mother has doubts about treatment prescribed.	Differing attitudes exist among physicians resulting in varying treatment.
21. As you go through it year after year, you become more knowledgable, you become a little more outspoken, forceful, brave, daring but at the same time...I couldn't even express them hardly, it just was hurting.	In spite of the hurt over having a child with mental retardation, over time parents learn to advocate on their child's behalf.	Parents learn to be adovcates for child's health needs.
22. I think they (physicians) felt out very closely the kind of people you are to start with. How caring or how capable you would be of giving the best for the child....They suggested that we get in touch with a lot of different organizations right away like this, supportive groups rather than pushing something along that line (institutionalization)	Mother perceived that physicians made judgements about family's coping ability resulting in supportive behavior rather than suggestions of insitutionalization.	Physicians did not suggest institutionalization at birth.

(table continues)

Excerpts from Transcribed Interview	Paraphrases	Themes
23. She was in Pampers for years and I finally got her off Pampers just before she started menstruating because I knew there would be a problem. This is at night. The day time no that's not. But at night we still can't. Beyond three hours up until 3 o'clock at night, forget it, she is wet.So what I do is I usually stay up and put her on at 11:30 or 12:00....And then I usually get up around 3:00 or 3:30 all the time. That's the only way we can deal with that.	Nightime incontinency is a problem. Parent must use extraordinary measures to maintain continency	Nighttime incontinency is a problem.
24. They don't understand what is going on, why. And to live with that for the rest of their life then have their tubes tied. I really fell that the alternative has to be there and I don't think that the individual can make that choice themselves. They're not capable of understanding to make that choice. And so I think that between a good doctor and parents, that choice should be left up to them in these cases.	Mother is concerned about sexual activity and pregnancy prevention. Birth control seems a logical choice and the decision should be left up to the doctor and the parents. Individual with mental retardation cannot make that choice.	Sexual maturity brings new health related problems.especially that of birth control.
25. And I mean she has her instincts now. They're there. It's constant. We just want to make sure tha she's not going to be taken advantage of.	Sexual maturity brings sexual abuse concerns	Parents concerned about sexual abuse.
26. I really do because I think it's (tubal ligation) less harmful to health than to be on birth control pills all their life. I really don't agree with that aspect of it from the health point.	Tubal ligation is preferred over birth control pills because it is less harmful.	Tubal ligation is preferred form of birth control.

(table continues)

Excerpts from transcribed interview	Paraphrases	Themes
27. You prevent problems by having the foresight or the planning. Whether its educational or medical or anoything like this.	Mother believes in anticipating problems and taking means to prevent them from occurring.	Prevent problems from occurring
28. He's (the dentist) a kid himself when he's with them. He jokes with them. He has the T. V. up above but he's got all these other things around him and it's a first name basis He's a very jovial person. He can talk to them. He can kid with them and yet he can get them to do it.	Dentist uses humour and familiarity successfully to accomplish his task.	Dentist understands child behavior and is at ease with the child.
29 And I think he (the dentist) is so sure of himself. I think they (physicians) are confident people themselves and confident in working with M. And that's why they're at ease and they're not afraid to say things or to do things or to make recommendations or whatever because they are very confident people.	Dentist is confident in his skills and is not intimidated by mental retardation.	Health care providers are confident individuals. Presence of mental retardation is not intimidating.
30. M. thinks of him as the doctor that tickles her, just a way of loosening her up. Gives her a nudge here or a little tickle or something like this. Just to get her going, put her at ease.	Physician uses techniques to help relax the child	Physician is at ease with the child and makes an effort to put child at ease.
31. I would say that they would be the doctors who, no matter how handicapped, how retarded, how sick a person would be, they didn't care what level of status you came from. They respect life. They respect life and no matter who, they would give their all	Mother views physicians she uses as being respectful of all individuals and providing equal care to all regardless of abilities	Caring physicians are those who provide equal treatment regardless of abilitiy or social status.

(table continues)

Excerpts from transcribed interview	Paraphrases	Themes
32. They are very much interested in the individual. They are very caring, dedicated people and the externals of who you are or where you come from or what level of ability you have is immaterial really. I think that they are just very, very caring. Very human	Mother views physicians she uses as being dedicated individuals who are respectful of their patients regardless of ability or social status.	Physician characteristic - are dedicated individuals who provide equal treatment regardless of ability or social status.
33. They're dedicated. They're very dedicated. "Money is not the important thing or how many patients I have on my load doesn't seem to be important or how much time I take is not the important issue." They are just competent. They are sure of themselves.	Mother views physicians she uses as being motivated more by altuistic values than by material ones.	Physician characteristic - possess altruistic value system.
34. Like even with the Synthroid too, the thyroid. Dr. T. right away shook his head and he said, "We're going to put her on Synthroid. There is no need for her not to have it like any other person. He says, "I know many doctors that would not do it."	Physician treated condition even though some physicians would not due to the presence of Down syndrome.	Treatment for some conditions varies due to the presence of Down syndrome.
35. Yes, I mean why give her that extra little bit to not be so tired or whatever. They would sort of indicate that they feel they're human. The human person equal to anyone else, having the same right as anyone else to all the care. There was no reason why they shouldn't have it. And I think that came through in different things they would say at different times.	Even when the physicians spoke they indicated that they treated the child as any other regardless of the presence of Down syndrome.	Presence of Down syndrome does not affect treatment carried out by physician.

(table continues)

Excerpts from Transcribed Interview	Paraphrases	Themes
36. He says,"Keep her active. Keep doing those things (participation in Special Olympics) That's wonderful." And even when he walks in he'll ask her, "Well how did you do? did you get another ribbon or something." He'll remember and he'll make a point of asking. And he encourages us in that way.	Physician takes an interest in other aspects of child's life and talks directly to the child. Physician is encouraging in remarks to parents.	Physician characteristic - is interested in the child's activities, talks directly to the child and encourages parents.
37 But once she reached 12 or was coming 12, now what are we going to do? You know you're at a loss. Sure we still can take her to swimming lessons as such but socialization is a very important part of it too. Where do we go? What do we do?	Parents were concerned about providing appropriate extra curricular activities once the child reached puberty	Puberty brings different concerns especially regarding extra-curricular activities.
38. Most helpful I suppose people who care, who have an interest in her (the child) and who care and who are supportive.	Interested, caring and supportive individuals have been most helpful	Caring individuals have been most helpful when obtaining health care
39. Least helpful I suppose when they treat her but just sort of push you off more or less I suppose. You don't get any satisfaction from it. They are not willing to communicate.	Physicians who are not interested in the child and do not communicate well to the parents have been least helpful	Disinterested physicians and those who do not communicate well have been least helpful.

(table continues)

Excerpts from the transcribed interview	Paraphrases	Themes
40. We had to take her in several times to have her eyes tested and, of course, they say at the younger age, too, it's very difficult and you go away and you really don't know anything more than what you went in for....I mean maybe they don't know how to treat or don't know if they should give her glasses at this point in time but I think there are ways and means of communicating those ideas too or discussing the whole idea.	Mother felt dissatisfied after eye appointment because information was not communicated to the parent.	Physician characteristic - good communication skills.
41. I would say its a lack of communication because either they don't want to say something if they are totally unsure or they just don't know. They may not know. Or they may not know how to treat mental handicaps. That's the other thing. I think some of them are very unfamiliar.	When physicians fail to adequately communicate results to parents it may be because they are uncertain of results or lack familiarity and experience with mental retardation	The ability of physicians to communicate with parents is related to their familiarity and experience with mental retardation

Table B-2

Higher Order Thematic Description of N's Experiences in Obtaining Health Care for her Daughter

Thematic Clusters	Generalized Descriptions
1. Physician characteristics (Excerpt numbers 1,9, 10, 12, 13, 14, 30, 31, 32, 33, 35, 36, 40, 41)	Helpful physicians have been those who are perceived as caring for the child and family, being available to the family, supportive of the mother's concerns. The presence of mental retardation in the child does not affect treatment prescribed; treatment is not based on ability or social status.. The physician expresses confidence in the mother's caring ability, is aware of the needs of the family and is knowledgable about community resources. He/she is at ease with the child and has skills that encourage cooperation. Physicians are dedicated individuals, confident of their abilities and able to put the child at ease. They possess good communication skills, are knowledgable and familiar with mental retardation.
2. Adolescent characteristics. (Excerpt numbers 2, 6, 7, 8, 23,)	Generally, the child is healthy now as compared to infancy when associated health problems required hospitalizations. As a child, M. was fearful of hospital situations resulting in uncooperative and uncontrolled behavior outbursts. Adolescence has diminished this fear but has brought new problems associated with sexual maturity, including birth control, sexual abuse and providing appropriate socialization experiences.
3. Mother's behavior (Exerpt numbers 2, 3, 21, 27)	Mother needed to shop around or look for physicians and other health care providers who could work with the child. Mother learned to use referrals from other individuals and acquired advocacy skills. Mother believes in preventative medicine.
4. Health care provision requires cooperation between parents and providers.(Excerpt numbers 4, 11).	Health care providers have worked together in a cooperative manner assisted by their location in the same hospital. Thus service provision has been coordinated
5. The local health units have not been supportive (Excerpt numbers 17, 18)	Interactions with the health unit staff left the mother discouraged. Information given by health unit staff did not seem to be current and differed from that obtained from other professionals with whom the mother was in contact.

(table continues)

Thematic Clusters	Generalized Descriptions
6. Experiences with health care providers at the birth of the child were supportive. (Excerpt numbers 15, 22)	Both physicians and nursing staff were supportive at birth assisting mother with feeding difficulties, providing psychological support and putting the parents in touch with supporting community agencies
7. Differing attitudes towards mental retardation exist among physicians (Excerpt numbers 19, 20, 34).	Not all physicians with whom the mother had contact shortly after the birth of the child were supportive and encouraging of raising a child with Down syndrome. Presently some physicians do not treat certain conditions associated with Down syndrome, such as hyperthyroidism.
8. Dentist characteristics (Excerpt numbers 2, 28, 29).	The dentist is able to relate to the individual with Down syndrome and put her at ease. He/she is confident of abilities and not intimidated by mental retardation.

Appendix C

The following two tables comprise the tabular presentation of the within-group theme clusters as described in the text (page 40).

Table C-1

Within group theme cluster analysis - Down's syndrome group

Theme	Fourth Order	Third Order	Second Order	First Order (Interview unique)
1.. Child characteristics	- child with Down Syndrome has associated health problems, - child required treatment for heart anomalies during neo-natal period.	- child is healthy now as compared to infancy period (kindergarten and adolescence).	- child/adolescent is cooperative with physicians, - is a unique individual , not just a sum of difficulities associated with Down's syndrome, - child with Down's syndrome has more health care needs than other children in the family.	- as a child was uncooperative in hospital, - adolescence has brought concerns regarding sexual maturity, -child does not easily indicate pain, - mental retardation makes some treatments difficult, - hospitalizations require a family member to be present, - family is lucky, things could be worse, - position in family might have made things easier for mom.

(table continues)

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
2. Mother characteristics and behavior	- has acquired advocacy skills to obtain services for the child.	- shops around to find physician with whom she could relate and who relates well to the child, - is knowledgable of child's health care needs and takes control, - networks with other moms and individuals for information and support.	- is primary care provider, - constantly monitors child's health, - is curious and needs to be informed, - realizes that physicians and the system are fallible, - priorizes health needs.	- needs encouragement and compassionate attitude from physician, - has high expectations of physicians, - wants role in decision making, - worries about drugs and side effects, - thinks creatively about care and treatment, - shopping around does not always solve problems, - is willing to make sacrifices for the health of the child, - respects physician decision even when conflict exists, - doubts about ability to care for the child, - realizes that she is lucky, - believes parents should have the choice of euthanasia at birth of child with DS.

(table continues)

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
3. Mothers feelings about experiences in obtaining health care.		- anger at birth of child, - anger at physician attitudes of disrespect and refusal to treat, - frustration at not being able to get needs met, - frustration when figuring out how the system works, - frustration at being shut out from expressing point of view - at not being viewed as part of the team.	- depressed at birth of child and in crisis situations, - distrustful of physicians.	- guilt at not being able to access physiotherapy, - doctor shopping is exhausting, - hurt at physician behavior that was demeaning to child, - worry over what will happen to the child.

(table continues)

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
4. Physician characteristics (Helpful)	- physician is at ease with the child and interacts comfortably displaying an attitude of acceptance, - possesses good communication skills, - physician includes mother as part of the caregiving team and works to help her achieve her goals, - sets an atmosphere of mutual trust.		- physicians are supportive of the mother's concerns, - aware of the needs of the family, - are dedicated individuals who take time to find out about patients, - helps parents to advocate and locate related services, - are willing to explore options with the family, - are creative in problem solving, knowledgable and familiar with mental retardation, - is not indifferent to the child but treats child like any other child, - has fathered/mothered a child with serious illness or mental retardation.	- is knowledgable about community resources, - is willing to admit when he/she doesn't know something about the child's condition, - possesses a sense of humour, - is able to put mother at ease and is sensitive to her psychological well being, - encourages mother and finds out as much about the child as possible, - needs to examine why he/she has become a physician, - is available.

(table continues)

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
Physician characteristics (Not helpful).		- specialists present particular problems (ignore mother input, do not value the child, are not perceived as being accountable for actions).		- holds key to some therapies, - is intimidated by mother, - rushed, does not have time, - is indifferent to child.
5. How services are delivered has been an important part of mother's experiences	- parents and physicians need to work together cooperatively to provide adequate health care because individuals with DS have limited communication skills	- problems with health care system include rushed physicians, impersonal service, and overburdened health care system, - some services not available to individuals with Down's syndrome	- children with Down's syndrome need primary care physician to coordinate specialist involvement,	- service provision has been coordinated in one hosptal, - service provision has been fragmented, - socialized medicine has been a savior, - service delivery should include parents right to choose active euthanasia, - mother must coordinate and monitor care provided by many physicians, - obtaining care has been like playing ping pong.

(table continues)

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
6. Hospital experiences including those at the time of birth and diagnosis.	- birth and diagnosis are traumatic/crisis times for parents		- hospital staff not prepared to meet emotional needs of family in crisis situations, - physicians and nurses provided good care and advice, - couple was informed of community services and received visit from parent.	- birth experience lacked suppprt, parental involvement in decision making and resulted in child being placed in foster care on advice of attending physicians, couple felt abandoned, - parents need to be supported at time of birth and diagnosis with information on services available, - parent needs to be involved in assessment process especially in information giving, - assessment instruments need to be valid for the child.

(table continues)

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
7. Societal issues regarding treatment and care of individuals with Down's syndrome		- families need to be supported from birth of child both psychologically and physically with services to enable them to cope with added stress of having a child with special needs, - there are many gaps in services or instances where services are being withdrawn, - cradle to grave services need to be provided if we are to continue to save the lives of infants with Down's syndrome and other infants with intense health needs.		
8. What has been most helpful?	- individuals who have been supportive of the mother in parenting role including physicians who consider her part of the treatment team and other mothers who offer knowledge, experience and empathy.		-publicly funded health care system so parents don't need to worry about cost of expensive procedures for these children,- - physician and nurse attitudes that value the child (i.e., caring)	

Table C-2

Within-group Theme Cluster Analysis - Severe Group

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
1. Physician characteristics (Helpful)	- caring individuals who are concerned about the child and the family, about mother's health too, - includes mother as part of care giving team.	- is knowledgable of community resources,puts parents in touch with resources, - is thorough in diagnosis, uses all available resources to reach conclusion, is informed and up to date - gives parents hope for their child.	- builds up mother's confidence, - is challenged by child's condition and seeks to find answers to difficult questions, - explains tests in manner mother can understand, - is honest.	- empathic attitude comes from having a child with difficulties, - makes mother feel at ease, - has a history with the family, they have shared many experiences together, - does not use stereotypic labels, - sees some of child's problems as treatable educates parents about practical aspects of disability, monitors child's development.
2. Physician characteristics (Not helpful)				- gives the impression of arrogance and assumes an all-knowing stance with mother, - because of limited numberof specialists, mother is not always able to find one with whom she can relate.

(table continues)

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
3. Child characteristics	- child's condition not evident at birth, was revealed gradually, - diagnosis difficult to obtain, - has eating difficulties, needs to be monitored, - has multiple problems (e.g., feeding difficulties, reduced ability to communicate, requires assistance with mobility or requires supervision, hearing impariment, self-destructive behaviors) - requires constant supervision, dependent on others for care.	- experiences seizures activity, - some conditions are chronic and unsolvable.	- is basically healthy now, health has improved since infancy.	- drugs to treat seizure disorder have led to life threatening situations, - overall diagnosis is still not available, - when hospitalized displays aggressive and uncooperative behavior and will not eat except in presence of mother, - is hyper-sensitive to anaesthetic and developed post operative asthma.
4. Mother characteristics	- networks with other mothers and parents to gain and share information regarding health condition, - is assertive and advocates for child in order to get services and equipment.	- wants to be considered part of the health care team, - shops around if necessary to get concurrent opinions or to find physician who concurred wtih her analysis of the situation, - took control over treatment and responsibility for the health of the child.after experiencing frustration with existing treatment or diagnosis.	- hopes for the best, always needs to see hope for the child, - needs to be informed, - realizes that physicians are human, is not critical of physician behavior, - is determined to find a diagnosis and searches every avenue until one is found, - locates information herself, - puts needs of her child before her own.	- see individual theme clusters.

(table continues)

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
5. Mother's feelings regarding experiences in obtaining heatlh care	- anger at some aspect of health care system including some physician/nurse behavior, waiting lists, system inequity, diagnosis (see theme clusters) - frustration over difficulty in obtaining services	- guilt over personal behavior that mother perceives as being detrimental to the child's well-being such as not getting a diagnosis sooner, administering powerful seizure control medication, inadequate eating schedules for the child.	- desperation at lack of diagnosis and lack of support after diagnosis, - worry over child's future	- confusion and shock at physician comments, - concern for other family members, - fear of effects of seizure medication, - grief, - hope for child's progress, - grateful for spousal support, - determination to prove diagnosis wrong, - despair, hopelessness,helplessness after diagnosis.
6. Hospital experiences	- staffing is not adequate to monitor the needs and health problems of these children especially seizure activity, - mother needs to monitor and oversee child's care in hospital.	- hospital staff not knowledgable or trained to meet the needs of these chidlren including mobility requirement, mode of communication, eating procedures.	- nurses are willing to share information with the mother.	- mother does not trust hospital staff, stays in hospital at all times when chid is admitted, - nurses try to meet the mother's requests and are more accountable for their actions, - a "rehab." nurse should be part of unit staffing, - some training in alternate modes of communication is important for nurses, - playrooms should be open on weekends, - hospitals overbook, - mother not included as part of treatment team.

(table continues)

Theme	Fourth Order	Third Order	Second Order	First Order (Interview Unique)
7. Service delivery			- waiting lists for some services are too long and promote developmental delay.	- our socialized health care scheme is in crisis which has particular impact on individuals with severe disabilities.
8. Diagnosis issues (mothers with school-aged children only). N=2			- diagnosis is shocking, devastating to the mother although physician may treat it as routine.	- mother was determined to prove diagnosis wrong, - experienced long term anger, perhaps because of abrupt and incomplete manner in which it was given, - mother was left with no hope for child.
9. What has been most helpful in obtaining health care?		- individuals such as a social worker or pediatrician who put mother in touch with support or service agencies		- other parents of children with disabilities because they listen, give good advice, are role models and are empathetic.
12. Societal attitudes				- since society values sustaining life regardless of conseqences, families of children with disabilities should have access to services that are required and should be recognized as performing a service that goes far beyond that of parenting.